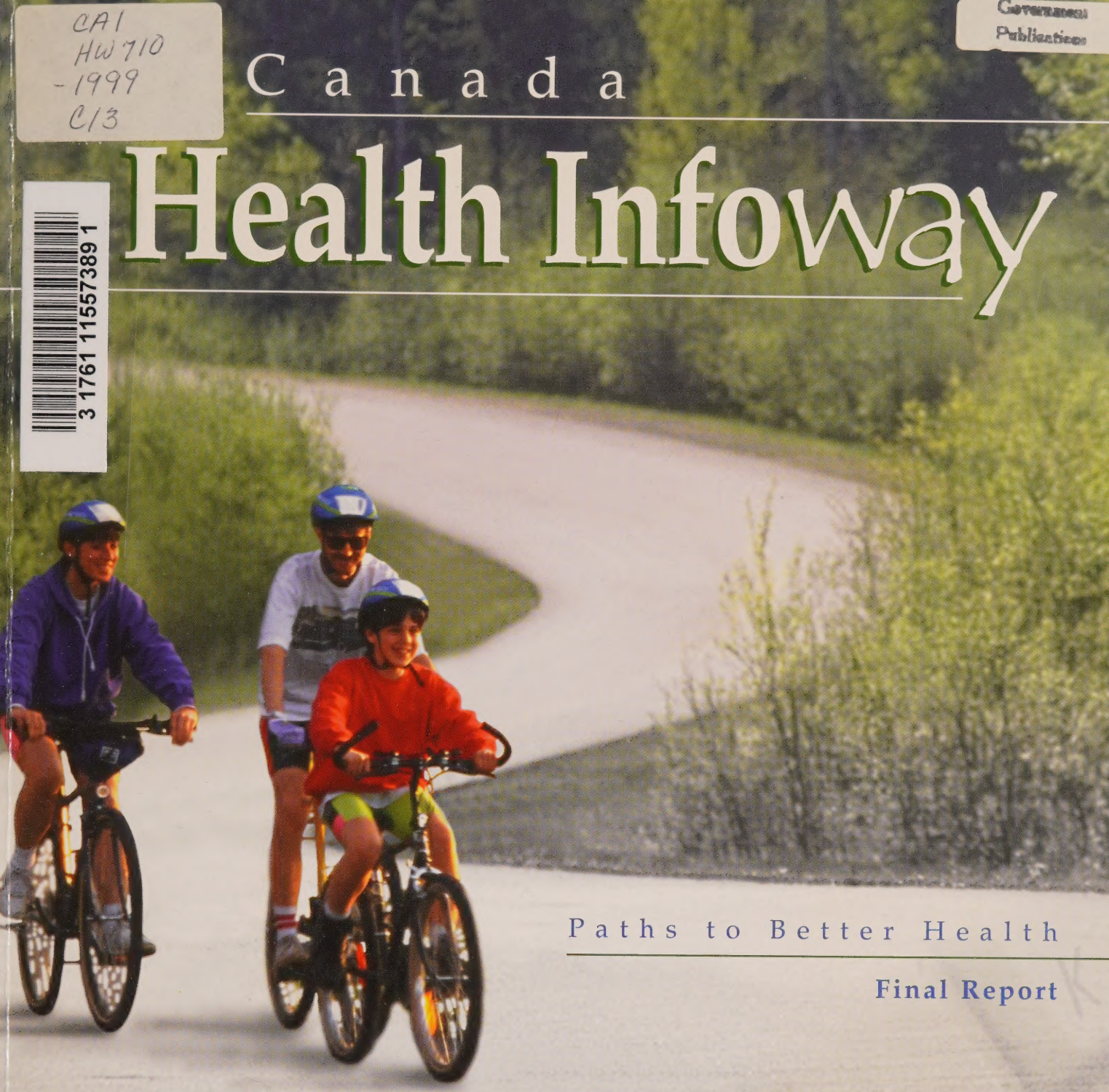
CA1
HW710
-1999
C13

Government Publications

Canada

Health Infoway

3 1761 11557389 1



Paths to Better Health

Final Report

Advisory Council on Health Infostructure

Digitized by the Internet Archive
in 2022 with funding from
University of Toronto

https://archive.org/details/31761115573891

The Honourable Allan Rock
Minister of Health
House of Commons
Ottawa, Ontario
K1A 0K9

Minister:

We, the members of the Advisory Council on Health Infostructure, are honoured to present to you our final report, Canada Health **Info**way: Paths to Better Health.

Over the course of our 18-month mandate, the Advisory Council met and worked with a number of collaborators. This included the provinces and territories, other federal departments, various health stakeholders, including health professionals and providers, policymakers, researchers and the general public, to develop a shared vision for a health infostructure, and identify its basic shape and the essential needs it should meet for Canadians. This report contains our conclusions, recommendations and proposed action steps for the development of the Canada Health **Info**way.

It is the Advisory Council's view that the Canada Health **Info**way will become the key information and communications foundation for our health care system in the 21st century. We also believe that the Canada Health **Info**way can, and will, result in improvements in the health of Canadians by bringing to them better health information, thus enabling better decisions to be made about their health and the health of others. The Canada Health **Info**way will also improve the health of Canadians by improving the efficiency and effectiveness of the health care system, and lead to increased accountability and responsiveness to Canadians' health needs.

As information and communications initiatives in the health sector continue to advance in all jurisdictions, we feel it is imperative that action be taken as quickly as possible. This must ensure that progress continues in an environment characterized by multi-sector collaboration, and, that there is recognition of common objectives for the health system to modernize and meet Canadians' evolving health needs. Steps that can be taken in the short term are detailed in our report.

Our mandate has given us the opportunity to study a number of issues central to preserving a health system that Canadians rely upon and still consider the best in the world. Efforts toward developing the Canada Health **Info**way will serve to further strengthen the system and benefit Canadians now, and in the future.

Respectfully submitted,
Members of the Advisory Council on Health Infostructure

Canada

Health Infoway

Paths to Better Health

Final Report

Advisory Council on Health Infostructure

February 1999

Canada

2000 Canada

This final report was prepared by the Advisory Council on Health Infostructure.

Additional copies are available from:
Health Canada Publications
Postal Locator 0913A
Brooke Claxton Building
Ottawa ON
K1A 0K9
Telephone: (613) 954-5995
Fax: (613) 941-5366

This report can also be downloaded from the Website address:
http://www.hc-sc.gc.ca/ohih-bsi

Questions and comments should be sent by mail to:
Office of Health and the Information Highway - Health Canada
Information, Analysis & Connectivity Branch
11 Holland Avenue, Tower A, 2nd Floor
Postal Locator 3002A2
Ottawa ON
K1A 0K9
Fax: 613-952-3226
E-mail: ohih-bsi@www.hc-sc.gc.ca

This publication can be made available on computer diskette, in large print, on audio-cassette or in braille upon request.

The opinions expressed in this publication are those of the Advisory Council on Health Infostructure and do not necessarily reflect the official views of Health Canada.

© Minister of Public Works and Government Services, 1999

Ce rapport est également publié en français sous le titre ***Info****route Santé au Canada : Voies vers une meilleure santé.*

Cat.: H21-145/1999E
ISBN: 0-662-27489-X

Table of Contents

Acknowledgements 1

Executive Summary 3

Our Health Depends on It 3

Values, Vision, Strategy and the Need for Cooperation 5

Empowering the General Public 7

Strengthening and Integrating Health Care Services 9

Creating Strategic Information Resources 10

Improving Privacy Protection 11

The Need for Harmonized Standards 12

An Aboriginal Health Infostructure 12

Technology Transfer and Public-Private Sector Collaboration 13

A Strategic Investment 14

Preface 15

Mandate 15

Process and Consultations 15

Next Steps 16

1. Toward a Healthier Canada 1 -1

What Is the Canada Health **Info**way? 1 - 1

Values and Vision 1 - 2

Strategic Framework 1 - 4

Cooperation – The Critical Success Factor 1 - 5

Key to Report 1 - 6

2. Empowering the Public 2 -1

Means of Empowerment 2 - 1

Health Information for the General Public 2 - 2

Ensuring Access 2 - 8

Public Input and Accountability – Promoting Citizen Engagement 2 -12

3. Strengthening and Integrating Health Care Services 3 -1

Health Care and the Canada Health **Info**way 3 - 1

Supporting the Health Care Team 3 - 3

Electronic Health Records 3 - 5

Seizing the Telehealth Opportunity 3 -11

4. Creating Information Resources 4 -1
The Need for Strategic Information Resources 4 - 1
Problems with Existing Information 4 - 2
Key Questions – Key Answers 4 - 4
Privacy Protection as a Design Feature 4 - 5
The *Health Information Roadmap* – An Action Plan for the 21st Century 4 - 5
Report Cards on the Health Care System 4 - 7
Need for a National Health Surveillance Network 4 - 8

5. Improving Privacy Protection 5 -1
Privacy Concepts 5 - 2
Key Legislative Mechanisms 5 - 2

6. Standards 6 -1
Standards and Privacy 6 - 1
Developing and Implementing Compatible Standards 6 - 2
Testing for Compatibility 6 - 3

7. An Aboriginal Health Infostructure 7 -1
A Unique Approach to Health Information 7 - 1
Steps Toward an Aboriginal Health Infostructure 7 - 3

8. Technology Transfer and Public-Private Sector Collaboration 8 -1
Technology Transfer 8 - 1
Public-Private Sector Collaboration 8 - 3

9. A Strategic Investment 9 -1
An Infrastructure for the 21st Century 9 - 1
From Promise to Reality 9 - 2

10. Moving Forward 10 -1

Glossary G -1

Annex A: Members of the Advisory Council on Health Infostructure A -1

Annex B: List of Recommendations B -1
Recommendations from Final Report B - 1
Recommendations from Interim Report B - 9

Acknowledgements

The Advisory Council on Health Infostructure wishes to give special thanks to Allan Rock, Minister of Health, who throughout our mandate has been enormously supportive in first providing the initial vision and mandate to the Council. He also encouraged us to explore the opportunities for marrying Canadian strengths and values in health care with the Canadian genius for developing and using information and communications technologies. The Council expresses gratitude to all those who took the time to share with us their ideas relating to a health infostructure for Canada. We are also grateful to all those individuals and organizations who prepared specific papers within extremely short deadlines to inform our discussions. As noted earlier, the Council especially appreciated the input from individual Canadians to our interim report. We also acknowledge the dedication, hard work and expert assistance from our Secretariat and other staff from the Office of Health and the Information Highway at Health Canada. Pierrôt Péladeau of the Centre for Bioethics at the Clinical Research Institute of Montreal provided us with invaluable advice on an ongoing basis throughout our mandate. Finally, the Advisory Council offers its sincere thanks to John Sifton, the writer for both our interim and final reports, who worked under tight time constraints to put our collective thoughts on to paper.

Executive Summary

Canadians see the publicly administered health care system as a defining feature of their identity. It is Canada's number one social program. Their support for it unites them across provincial, territorial, cultural, linguistic and socio-economic boundaries. For as long as many Canadians can remember, they have believed that it will be there for them if they fall ill or have an accident. That confidence has contributed greatly to the Canadian quality and way of life for almost 40 years.

But now and in ever-increasing numbers, Canadians are starting to worry that the system will not be there when they need it – and may not be there now. They worry about the ability of the system to provide universal access to comprehensive care when and where they need it. They worry that the major changes taking place in the health care system – regionalization, hospital restructuring, shifts toward community-based care – may be degrading the quality of care. Beyond the short-term anxieties, Canadians want to be assured that the health system will be up to their needs in the 21st century. All too often they feel too isolated and uninformed to be able to turn this concern into constructive action.

This report is about how new information and communications technologies strategically deployed in a pan-Canadian health information highway (Canada Health **Info**way, for short) or infostructure, can help to empower Canadians with better health information and new opportunities. This report is also about how the Canada Health **Info**way can help significantly to improve the quality, accessibility, portability and efficiency of health services across the entire spectrum of care. It is also about how the **Info**way can enable the creation, analysis and dissemination of the best possible evidence from across Canada and around the world as a basis for informed decisions by patients, citizens, informal caregivers, health professionals and providers, and health managers and policymakers.

In the Council's view, the Canada Health **Info**way will become the key information and communications foundation for our health care system in the 21st century. It will also become a powerful contributor to improvements in the health of Canadians.

What is the Canada Health **Info**way or health infostructure? The term refers not just to the use of information and communications technologies in health. It also refers to the health information the technologies create, the policies governing use of this information, and the people and organizations who create the information and use this infrastructure.

The Canada Health **Info**way will also not be a single massive structure. It will be built upon the foundation provided by provincial, territorial and federal health infostructure initiatives already being designed or implemented. Each will retain its identity and integrity. It is the vision of the Canada Health **Info**way which allows these diverse initiatives to complement each other in improving the health of all Canadians.

Our Health Depends on It

Our health affects everything we do. Nothing is more basic to our existence. When we think about it, we usually think of lifestyle choices and access to quality care. To a lesser extent, we may think about the provision of services to protect our health. What we often forget is the large degree to which both of these depend on good information and effective communications which a health infostructure or Health **Info**way can deliver. Some of the main benefits that will be realized will be described below.

Because of health reform and restructuring, Canadians are increasingly anxious that the health care system will not be there when they need it. But they lack consistent access to reliable information on where to go for the best treatment, how well health care programs and services serve patients, or on the overall performance of the health care system. The Canada Health **Info**way will provide Canadians with report cards on health care programs and services, and solid information on the health care system as a basis for consumer choice, assessing the health of their communities, holding the system accountable and providing input into health policy.

Patients and informal caregivers want more information on where to go for help, on the treatment options available to them, and on strategies to protect their health. And many Canadians want to be more informed about whether their lifestyle or nutritional choices are truly healthy. However, while ever more health information is becoming available through the media and the Internet, it is hard to distinguish reliable information from that developed to promote a product or crank remedy. The Canada Health **Info**way will allow the development and dissemination to Canadians of evidence-based information on treatment options, healthy lifestyles and emerging health concerns in many different ways. This will give people new means of obtaining insight and support when making personal health care decisions.

During an emergency in the middle of the night or when travelling to another province, it is often impossible for patients to ensure that the health care professional or provider on the scene has access to their health history. The Canada Health **Info**way will let patients provide access to critical information in their health records 24 hours a day, seven days a week, with fuller assurances of confidentiality than can be provided today with a paper-based system.

Most of the first-time patients visiting doctors' offices, community clinics and hospital outpatient clinics or emergency wards bring with them little or no medical history, only their own subjective impressions. This situation adds a potentially dangerous haphazardness to diagnostic and treatment decisions. Even if the patient brings a record from a physician or health care professional, it is incomplete and unhelpful in all too many cases. The Canada Health **Info**way has the potential to ensure that patients can allow appropriate and timely access to their medical histories by health care professionals and providers, thereby ensuring that diagnoses and treatment decisions are made with a full knowledge of the patient's background.

Because it is so difficult to gain access to past information on patients, health care professionals and providers often order potentially avoidable tests and x-rays, adding to health care costs and sometimes creating potential risks for patients. The Canada Health **Info**way will dramatically reduce the chances that patients will be subjected to expensive, potentially unnecessary, redundant and sometimes risky tests and x-rays.

Health reform and restructuring have created a much more complex health care system in which it is increasingly difficult to prevent patients from slipping between the cracks. Coordination and keeping track of patients is a challenge for newly merged hospitals and medical facilities with campuses in several locations. Only the most basic data are often available on public health, home care services, and community health and long-term care institutions which have emerged during the last decade and a half. The Canada Health **Info**way will provide the information and communications infrastructure that will allow the seamless delivery of patient care across the wide range of diverse institutions composing today's complex health system.

Because the amount of specialized information for health professionals is growing exponentially around the world, it has been estimated that practitioners would have to read 19 articles a day, 365 days a year, to keep up-to-date. Instead of being able to sift through everything to find the best information, they may have to search for information from more accessible local sources or may find that available information is irrelevant. The Canada Health **Info**way has the potential to provide health care professionals and providers with convenient electronic access to the right up-to-date information at the right time from around the world through clinical decision support systems and new learning tools which will allow them to upgrade their knowledge and maintain competency.

For people in remote or rural areas or requiring very specialized forms of treatment, costly travel to metropolitan areas where the necessary expertise exists is often the only option for securing a needed treatment or diagnosis. Meanwhile, because of isolation and the difficulties of being the only professional or provider for a remote and widely scattered population, it is increasingly hard to keep doctors and nurses in rural and remote areas. The Canada Health **Info**way can provide the communications facilities to bring needed medical expertise to remote and rural areas, to support and upgrade professionals and providers in those areas, and to provide Canadian patients with access to the best expertise in the world.

In the 1980s and 1990s, health managers have faced many difficult decisions on everything from how to cut budgets to how to restructure their institutions without compromising patient care. While mountains of information exist and everyone has a strong opinion, very little solid empirical information is available to help managers make the best decisions. The Canada Health **Info**way will provide health managers with much needed empirical information on the health impacts, as well as the financial and administrative implications, of their decisions.

In the name of health reform, policymakers have made many difficult decisions over the last 15 years on everything from reductions in the number of hospital beds to levels of coverage for the costs of prescription drugs. Although much information is available on these issues, there is a shortage of hard, empirical information on health effects. In many cases, the means of gathering information to evaluate the health and cost implications of decisions already made simply do not exist. The Canada Health **Info**way will provide health policymakers with critical evidence and feedback for evaluating the effects of past decisions and projecting alternative scenarios to illuminate the implications of future decisions.

Although our understanding of medicine and health is growing by leaps and bounds, it is often impossible to find information relevant to a particular environmental hazard or a specific patient with a specific ethnic background, lifestyle and socio-economic status – to mention only a few of the variables relevant to an understanding of non-medical determinants of health. Nor do we systematically exploit the vast amounts of data we already have on the outcomes of medical interventions. The Canada Health **Info**way should allow researchers to reach new and fundamental understandings of health determinants, both medical and non-medical, with possibly far-reaching implications for our own health as well as the quality and cost of health care.

Each federal, provincial and territorial jurisdiction now takes a different approach to privacy, with the result that the level of protection varies greatly across the country. At the same time, the level of security in hospital record offices and in physicians' offices can leave much to be desired. Most people do not know how to gain access to their records, while the rules governing how much of a person's file a health care professional or provider needs to see are often vague. A key foundation of the Canada Health **Info**way will be the harmonization upward of provincial, territorial and federal privacy legislation for privacy protection in the health sector. Another will be the implementation of fair information practices and privacy-enhancing technologies throughout the health sector. In addition to giving people greater control over their health records, these will involve strict and explicit controls on access to such records, including making them available to health care professionals and providers only on a "need-to-know" basis.

Values, Vision, Strategy and the Need for Cooperation

European countries, Japan and the United States are all investing heavily in information and communications technology applications for the health sector. In September 1998, the British government released an ambitious and far-ranging strategic plan to spend more than £1 billion over seven years on such an initiative. Canada's expenditures on information technology in the health field are expected to rise from less than $1 billion a year in 1996 to more than $1.5 billion by the year 2000.

Much of this money is now being used to build health infostructures at the provincial, territorial and regional levels. These, in addition to key federal initiatives such as the Canadian Health Network, the National Health Surveillance Network and the First Nations Health Information System, represent essential building blocks for the Canada Health **Info**way. But right now there is no collective vision or overall pan-Canadian strategy to guide how this money is being spent.

*"... and foremost, the Canada Health **Info**way should strengthen ...licare as a single-payer, publicly ... health care system guided ... five principles of the ...da Health Act...."*

As a Council, we believe the values for this vision should be the same ones that underpin Canadians' support for our health care system. First and foremost, the Canada Health **Info**way should strengthen Medicare as a single-payer, publicly funded health care system guided by the five principles of the *Canada Health Act* – universality, accessibility, comprehensiveness, portability and public administration – within the framework of a strong federal, provincial and territorial partnership. The values of fairness and compassion underlie these principles and will help shape the evolution of the Canada Health **Info**way.

Privacy must also be a key value in the Canada Health **Info**way. We believe that the level of privacy protection on the Canada Health **Info**way has the potential to be higher than in today's paper-based world.

Chapter 1 discusses other values which will be central to the development of the Canada Health **Info**way. It is the marriage of these values with a sense of new technological capability that provides the foundation for our vision of the Canada Health **Info**way. That vision is as follows:

> *The Canada Health **Info**way empowers individuals and communities to make informed choices about their own health, the health of others and Canada's health system. In an environment of strengthened privacy protection, it builds on federal, provincial and territorial infostructures to improve the quality and accessibility of health care and to enable integrated health services delivery. It provides the information and services that are the foundation for accountability, continuous improvement to health care and better understanding of the determinants of Canadians' health.*

This vision is very people-focused. The individuals whom the Canada Health **Info**way should empower include individual Canadians, in their roles as patients, informal caregivers, citizens or consumers of health information; physicians, health care professionals and providers; and health researchers, managers and policymakers. The communities to be served by the Canada Health **Info**way range from local communities to Aboriginal communities to organizations to geographically dispersed communities of interest defined by a particular health concern or issue.

The realities of the Canadian health system at the millennium have shaped our strategy for the Canada Health **Info**way. It flows from a recognition that people are concerned about the health system, want to take more responsibility for their own health, and are demanding greater accountability from the system. It stems from a realization that lack of coordination across the spectrum of health care services is a major source of inefficiency and public anxiety. It is based on the perception that health care professionals and providers need to keep abreast of the global explosion in health knowledge. Its foundation is a respect for provincial and territorial jurisdiction in health care delivery and a recognition that provincial and territorial health information systems represent the building blocks for the Canada Health **Info**way.

For the core of this strategic framework, the Council has stated four strategic goals for the Canada Health **Info**way:

- empowering the general public;
- strengthening and integrating health care services;
- creating the information resources for accountability and continuous feedback on factors affecting the health of Canadians; and
- improving privacy protection within the health sector.

Until now, health infostructure developments across Canada have occurred without sufficient consideration of how they will ultimately fit together into a Canadian system. The federal government will be critical to the success of the Council's strategy by acting on its responsibility to foster mutual cooperation and collaboration among provincial and territorial governments, Aboriginal communities, and all stakeholders in developing and implementing the Canada Health **Info**way. Whatever the outcome of ongoing discussions about a new "social union" in Canada, partnership among all levels of government will be crucial to fulfilling the potential of the Canada Health **Info**way. Only a pan-Canadian health infostructure will fully capture the benefits – in terms of health care portability and large population research on interventions and determinants of health – implicit in the capabilities of the new information and communications technology.

Empowering the General Public

The Canada Health **Info**way should empower members of the public to make informed choices about their own health, their health care and about health policy.

For this to occur, three conditions must be met.

- First, the Canada Health **Info**way must provide Canadians with credible information that will be useful to them as citizens, as patients, as informal caregivers or simply as laypersons interested in making healthy choices about nutrition or lifestyles.
- Second, people should actually have equitable and affordable access to the infostructure and to the information it makes available.
- Third, the infostructure should allow opportunities for communities to become involved in holding the health system accountable and provide input into health policy.

Health Information for the General Public

In the Council's view, federal, provincial and territorial health ministries must recognize in their funding decisions that health information is an essential public good which should be readily available and accessible to all Canadians as a component of Canada's publicly funded health system. This information should include whatever might help Canadians facing decisions about their own health or trying to hold the system accountable.

Because of the general public's diversity, these health information needs are not fully understood and deserve further investigation using a variety of culturally appropriate, interactive and ongoing strategies. Many members of the public also do not know how to use information technology. To promote further their ability to access and use empirically based health information, the federal government should support demonstration projects of applications for this purpose. As well, Health Canada should establish a fund to support efforts by consumer and health intermediaries to provide the public with access to consumer health information. These non-profit intermediary organizations now meet many of the public's health information needs.

"... health information is an essential public good which should be readily available and accessible to all Canadians as a component of Canada's publicly funded health system."

To help the public distinguish objective, empirically based health information from promotional data, Health Canada, in partnership with provincial and territorial health ministries, should take the lead in ensuring the development and implementation of standards for such information. These should eventually evolve into rating criteria for websites providing health information. It will also be important to ensure that health concerns – such as consumer protection with respect to health products and services – are adequately reflected in the present work of governments in developing legislative and regulatory frameworks for electronic commerce on the Internet.

In health as in other areas, there is now far more information on the Internet in English than in French. For this reason, Health Canada should work with other federal departments and agencies and specialists in the field to encourage development of an Internet search capability which is specific to health and, at a minimum, fully and equally meets the needs of Canada's English- and French-speaking communities.

The policies and practices now in place to recover costs or generate revenues from making publicly funded government information available are another of the obstacles to obtaining free health information. Health Canada and representatives of user communities should take the lead in encouraging the federal government to review these policies and practices.

Ensuring Access

It is paramount that there be universal, affordable, equitable access throughout Canadian society to the Canada Health **Info**way. To this end, the federal government should continue to ensure universal, equitable and affordable access to basic telecommunications infrastructure, now and in the future. Health Canada should also take a leadership role in ensuring that health information and health care applications for the public are developed to be accessible to all citizens, irrespective of their geographic location, income, language, disability, gender, age, cultural background or level of traditional or digital literacy.

...paramount that there be ...versal, affordable, equitable ... throughout Canadian ...ciety to the Canada Health ...

Not all Canadians will be in a position to access health information over the Internet. Thus, investments in the digital networking of the Canada Health **Info**way should be balanced by appropriate investments in the other (i.e. non-electronic) ways for sharing information that can lead to improved health.

A real need exists to establish on the Internet a "Canada Health Space," a universally accessible health information/communications commons governed by Canadians in the public interest. In such a Canada Health Space, every individual or organization with products or activities affecting health would report on their health implications. The Canada Health Space would be operated by health intermediaries – libraries, community health information centres, clinics, health promotion organizations, etc. – which represent major sources of health information for many members of the public.

The nation-wide networking of these organizations will create a new opportunity to distribute health information. This networking deserves support from Health Canada, in partnership with other federal departments, provinces and territories, and health stakeholders. This assistance should take the form of funding and technical support, and should be budgeted for as a normal cost of doing business electronically. A concerted effort should also be made to ensure that all public and not-for-profit health care institutions in Canada are aware of Industry Canada's Community Access Program, and how they can apply for resources to locate public electronic access facilities on or near their premises.

As a means of ensuring more equitable access to health information and health care services, Health Canada, in partnership with provincial and territorial health ministries, should work closely with the Canadian Network for the Advancement of Research, Industry and Education (CANARIE), and Industry Canada to investigate the further integration of new technologies, including satellite technologies, into health networks at all levels.

Public Input and Accountability

The Internet is now connecting communities of like interest – independent of distance and at very low cost – by allowing people to exchange information electronically, develop common positions and take collective action on issues at every level. However, the groups representing the public are voluntary organizations wholly dependent on volunteers' time, energy and financial resources. The public is also diverse. People with disabilities, seniors, women – to mention only a few – will each have a unique view on the shaping of health policy, the Canada Health **Info**way and the information it carries.

The Council believes there is a serious need for Health Canada to establish an independent office of citizen health advocacy to coordinate and facilitate input and participation by these diverse publics into health policy deliberations, specifically policies relating to the Canada Health **Info**way. A key role of this office would be to ensure that assessments and evaluations of health sector activities relating to the general public are produced, and that they are available and accessible to the general public. This would involve setting the agenda for, and demanding action on, report cards addressing the performance of health care programs and services, outcomes from interventions and treatments, and the actual health impact of health and other public policies.

Strengthening and Integrating Health Care Services

In addition to strengthening health care by encouraging a more informed and involved public, the Canada Health **Info**way will directly contribute to significant improvements in health care services. It will provide health care professionals and providers with the communications and information tools and supporting environment they need to improve the quality, accessibility, portability and efficiency of health care services.

Supporting the Health Care Team

Central to health care are the health care professionals and providers who actually deliver care. Without their active support and use of the new tools offered by the Canada Health **Info**way or its provincial and territorial components, little will change and evidence-based decision making will remain more a promise than a reality.

Federal, provincial and territorial governments should develop and test incentives to encourage and assist health care professionals and providers to adopt health infostructure applications. Governments, in collaboration with associations of health care professionals, should also fund training to help these groups acquire the necessary digital skills, as well as to participate in developing, piloting and evaluating tools to support clinical decision making. In the Council's view, it would also be prudent to put in place a labour force strategy to address the impact of these changes upon health care professionals, providers and workers, and to make sure that the necessary skills and knowledge are in place.

"The Council believes there is a serious need for Health Canada to establish an independent office of citizen health advocacy...."

Electronic Health Records

Patient-based health records are fundamental to provincial and territorial health infostructures. However, they have the potential for serious violations of privacy. The Council believes that, with particular care, electronic health records can actually enhance privacy protection, improve patient care, enable telehealth, empower citizens through greater control of their own health records and serve as the foundation for an ever-improving information and evidence-based health system.

The federal Minister of Health should work with his provincial and territorial counterparts to improve patient care through the creation of provincial and territorial person-based, electronic health record systems. These systems would make accessible – on a need-to-know basis and under the control of patients – all relevant information about their past medical histories.

*"Central to health care are the health care professionals and providers who actually deliver care. Without their active support and use of the new tools offered by the Canada Health **Info**way...little will change and evidence-based decision making will remain more a promise than a reality."*

As one means of protecting patients' privacy, Ministers should ensure that legislative safeguards are in place against the use of personal identifiers in health for purposes outside the health field. Also critical will be measures to improve the security of health records by taking advantage of modern technologies such as encryption, authentication and the electronic logging of all accesses made to a personal record.

"The Council believes that, with particular care, electronic health records can actually enhance privacy protection, improve patient care, enable telehealth, empower citizens...."

In the Council's view, federal, provincial and territorial governments should work together to ensure a transparent and harmonized approach across the country – in light of the principles in the report – to conduct ethical reviews on a case-by-case basis of proposed health research projects that require access to individually identifiable records and that cannot be done on the basis of informed consent of patients. Such ethical reviews would assess whether there is sufficient public good expected as a result of a proposed project to warrant the project and the possible invasion of privacy. To this end, governments should consider establishing an independent oversight mechanism to ensure that ethical review panels across the country operate in a manner consistent with the principles in the report; and/or creating, if necessary in their respective jurisdictions, ethical review panels which would operate in accordance with those principles.

"Telehealth can help link the diverse services in today's complex health system into an integrated whole...."

The evolving provincial and territorial health information systems should also have a system architecture that makes it possible to exchange information under the strictly controlled circumstances as presented in this report. Finally, provincial and territorial privacy legislation should be harmonized to facilitate these objectives.

Seizing the Telehealth Opportunity

Telehealth can help link the diverse services in today's complex health system into an integrated whole and ensure that they operate in a fully coordinated fashion. Telehealth applications can also enable the health care system to deliver better quality services electronically to previously underserviced rural and remote areas and help local health care professionals and providers to deliver better care.

Information, wisely and strategically used and made available in a way fully respecting individual privacy, will be a basic foundation of the Canada Health ***Info****way."*

Federal, provincial and territorial Ministers of Health should establish a telehealth task force to develop a Canadian strategy for integrating telehealth into health care delivery. To create a knowledge base for the task force, funding should be made available to develop broadly accepted frameworks for assessing the value of telehealth applications, undertaking telehealth pilot and demonstration projects, assisting national telehealth organizations, supporting telehealth training for health care professionals and providers, and assisting research on the ethical, legal and social issues associated with telehealth.

Providing telehealth services across jurisdictional boundaries can raise complex issues because of differences among jurisdictions in legislation, regulations and professional requirements governing delivery of health care. For example, when services are provided across jurisdictional boundaries, how will health care professionals and providers be reimbursed? If something goes wrong, who will be accountable? Several professional associations are examining these issues, and the Council calls for further measures to build on these efforts.

Creating Strategic Information Resources

Information, wisely and strategically used and made available in a way fully respecting individual privacy, will be a basic foundation of the Canada Health **Info**way. Such information can go a long way toward ensuring that Canada's health system continues to improve and becomes more accountable to Canadians. Serious gaps and flaws exist in the information now available. These must be filled if the full benefits of the Canada Health **Info**way are to be realized.

In the Council's view, the report, *Health Information Roadmap: Responding to Needs*, developed by the Canadian Institute for Health Information (CIHI), Statistics Canada and Health Canada, fully lays out a plan to create information resources to support accountability and continuous feedback on factors affecting the health of Canadians. In the context of the stringent privacy safeguards, confidentiality requirements and data security arrangements described in Chapters 3 and 5, this plan provides for:

- the integration of standardized data to allow comparisons and new insights;
- expanded or new data coverage for health services, medical interventions, health determinants and the costs of services;

- data exchange and connectivity; and
- increased analytic expertise and the dissemination of results.

The federal Minister of Health should commit the necessary levels of funding (as detailed in the report) to ensure successful implementation of the plan.

The plan includes report cards to the public to improve the overall accountability of the health care system. Such report cards would be based on evaluative analyses and consensus building to develop yardsticks and fair measures of health care system performance and Canadians' health status.

As well, federal, provincial and territorial Ministers of Health should collaborate in supporting the development of a National Health Surveillance Network that will enable timely monitoring of the health of a region, province, territory or the nation as a whole in a global context.

Improving Privacy Protection

Significant variations now exist in provincial and territorial laws, regulations and guidelines for privacy and the protection of personal health information. This diversity could seriously hamper development of the Canada Health **Info**way. In its interim report, the Council called on the federal Minister of Health to take the lead in encouraging an accord among provincial, territorial and federal governments to harmonize – taking into account best practices internationally – the approaches in their respective jurisdictions to privacy and the protection of personal health information.

In harmonizing, governments should ensure that their privacy legislation for health embodies a clear definition of health information, broad enough to incorporate health information collected in public and private systems. Such legislation should ensure that equal obligations and penalties apply to both public and private sectors. It should also include a definition of personal health information which takes into account the spectrum of potential identifiability.

The legislation should incorporate a definition of a custodian or trustee of personal health information, and a custodian or trustee's obligations. It should ensure that these obligations apply equally to private sector organizations and organizations acting as an agent or contractor for the custodian. As well, it should define a guardian (e.g. for a minor child or a mentally incompetent person) and a guardian's obligations.

The legislation should define what constitutes informed consent, as well as provide a clear statement of principle to the effect that informed consent should be the basis for sharing information. It should define "exemptions" to this requirement for informed consent and give clear guidance on how to balance the right of privacy with the public good for research purposes.

Such legislation should prohibit all secondary commercial use of personal health information and set clear limits on access and use of health information by third parties outside the health care system. It should contain provisions regulating secondary uses of non-identifiable health information, taking into account the range of potential identifiability of such information. Finally, it should prohibit the use of personal identifiers in health for other purposes.

"...legislation should prohibit all secondary commercial use of personal health information...set clear limits on access and use of health information by third parties outside the health care system...contain provisions regulating secondary uses of non-identifiable health information...prohibit the use of personal identifiers in health for other purposes."

The Need for Harmonized Standards

The Canada Health **Info**way will not be only one massive structure. It will be composed of provincial and territorial as well as federal health infostructures and those of regional health authorities. Each of these will retain its identity and integrity.

The Canada Health **Info**way will have the potential for two kinds of information transfers among provincial and territorial health infostructures.

- First, the **Info**way should allow for the possibility of transfer of a patient's health record for the purpose of treating that patient and subject to his or her control.
- Second, the **Info**way should allow the precisely controlled pooling of information from provincial and territorial health records for research purposes, under the conditions in Recommendation 3.4 and legislative provisions in Recommendation 5.1.

"Despite significant progress, Canada has a long way to go in developing compatible standards."

For such controlled interconnections to be possible, it will be necessary to achieve a significant level of harmonization among the standards used in provincial and territorial health information systems.

Despite significant progress, Canada has a long way to go in developing compatible standards. The Council in its interim report recommended that Canada should develop a strong Canadian capability for cooperatively managing the development and adoption of compatible standards in the areas of health information and telematics, with strong links to international standards deliberations.

Such a strong Canadian capability can be achieved only if CIHI receives sufficient funding for standards development from federal, provincial and territorial governments. Its partnership initiative should be expanded to allow greater participation by citizens. Because health care is largely publicly funded and administered, it is critical that CIHI have a formal process for identifying, ratifying and implementing standards in conjunction with federal, provincial and territorial Deputy Ministers of Health. CIHI should also continue to play a lead role in Canada with respect to international standards deliberations in the area of health informatics and telematics. Finally, Industry Canada and the Standards Council of Canada should establish a standards development organization for health informatics and telematics based on a partnership between CIHI and the Canadian Standards Association, drawing on the strengths of both organizations.

The Council believes it is only prudent for Health Canada to work with CANARIE and other organizations to ensure that facilities are available to test the compatibility between new and existing products before actual use on networks forming the Canada Health **Info**way. Because many compatibility issues can be resolved only in practice, Health Canada should also offer incentives for provincial and territorial governments to work jointly on projects to refine and resolve such issues.

An Aboriginal Health Infostructure

Health Canada has a long-standing responsibility for providing health care services to First Nations and Inuit communities. The Council thus commissioned two papers by the Assembly of First Nations (AFN) to explore Aboriginal health information needs and the potential of an Aboriginal Health Infostructure. The recommendations made in those papers provide a strong foundation for advancing the health infostructure in Aboriginal communities and should be used in consultations with representatives of all Aboriginal communities.

Because of the uniqueness of the situation and health information needs of Aboriginal communities, Health Canada should consider an Aboriginal Health Infostructure, strategically interconnected to the Canada Health **Info**way, as an autonomous and distinct institutional development consistent with Aboriginal interests. Aboriginal groups should also receive financial resources to undertake further consultation and communications with governments, private sector groups and each other, as a means of confirming and further developing the concept of the Aboriginal Health Infostructure and defining plans for its development and implementation. Resources committed and dedicated for capacity development and training should be specifically designated for Aboriginal people to support the Aboriginal Health Infostructure and Aboriginal participation within the Canada Health **Info**way.

An important health information resource for Aboriginal people will be the First Nation and Inuit Regional Longitudinal Survey. Health Canada, in partnership with other federal departments, should support and fund this survey to enable a sustained, ongoing, comparable source of First Nation and Inuit population health information, data collection, research and analysis capacity within a process validated and supported by the First Nations and Inuit peoples, both regionally and nationally. Health Canada should also provide additional resources for the First Nations Health Information System, but only on a sustainable basis and in the context of developing a comprehensive Aboriginal Health Infostructure. The Aboriginal Health Infostructure will consist of a multifaceted, interlinked process involving many initiatives – some currently under way and others to be developed.

Most remote and rural Aboriginal communities lack the communications infrastructure to support reliable high-speed transmission or reception of data, images or text. Health Canada should take the lead, with other federal departments, to ensure that the state of the communication infrastructure in Aboriginal communities is assessed. This investigation should be conducted with a view to undertaking technical enhancements to support high-speed data transmission and enable accessible, affordable and reliable use of the Canada Health **Info**way with service levels comparable to those in similar non-Aboriginal communities. Development and implementation of the health infostructure in Aboriginal communities should also involve a sustained commitment to developing an economic infrastructure in those communities.

*"Because of the uniqueness of the situation and health information needs of Aboriginal communities, Health Canada should consider an Aboriginal Health Infostructure, strategically interconnected to the Canada Health **Info**way, as an autonomous and distinct institutional development consistent with Aboriginal interests."*

Technology Transfer and Public-Private Sector Collaboration

The ongoing revolution in information and communications technology remains one of the driving forces behind development of the Canada Health **Info**way. The pace of change continues to grow. In five years, the technological landscape may look very different. New health care applications in the areas, for example, of tele-homecare or telehealth will likely have far-reaching implications and provide the basis for new kinds of services to patients and the public.

If Canada's health care system is to benefit fully from these technological developments, health care professionals, providers and institutions must be involved in monitoring and adapting information and communication technology to health needs. Health Canada should take the lead in developing, in cooperation with other federal departments, provincial and territorial ministries and professional and institutional associations, a process to involve providers and institutions in such monitoring. This process should also help them take advantage of information on best practices and evaluations relating to the deployment of these technologies in health. Incentives and other means should be used to promote ongoing innovation in the use of this technology to deliver health information and health care services. Finally, it will be critical to address the human and behavioural impacts of adopting information and communications technology in health.

Collaboration between the public and private sectors can be an effective way of ensuring the development or adoption of technology within the health field. In this context, we mean technology such as hardware, software, systems design, system architectures, etc. We do not mean data or service delivery, which can raise sensitive issues, including the possibility of some eventual privatization.

The Council believes that government has the responsibility to define clearly its approach to public-private collaboration and transparently examine its implications in light of the following principles. All such collaborations must pay fastidious attention to safeguarding privacy and protecting health information. They should also respect and reinforce the principles of the *Canada Health Act*, particularly public administration of the health system. As part of the normal contracting process where intellectual property with a potential for commercialization is likely to be developed, the return to the parties should be in line with the contributions made and the risks assumed by the parties. To the extent possible, commercialization of intellectual property should occur in Canada.

A Strategic Investment

Funding for the Canada Health **Info**way is not an investment where short-term payoffs provide a sufficient rationale. The Canada Health **Info**way will be a strategic infrastructure that will transform and have impacts on the Canadian health care system and the health of Canadians in the long term. It is a positive revolution in the making. Investments in health infostructure – and in its essential building blocks at the provincial and territorial levels – must take the long-term view. Through such investments, we will help to create the Canadian health care system of the 21st century – one in which the public attains a new level of empowerment, health care services are stronger and much more integrated, new information resources enhance accountability and decision making at all levels, and privacy protection is significantly improved.

*"The Canada Health **Info**way will be a strategic infrastructure that will transform and have impacts on the Canadian health care system and the health of Canadians in the long term. It is a positive revolution in the making."*

However, these long-term benefits are poorly understood. In partnership with provincial and territorial ministries of health, Health Canada should therefore undertake public awareness campaigns at the community level to emphasize the importance of strategic health infostructure investments.

To ensure that such benefits are fully realized, it will be necessary to promote collaboration, information sharing and mutual learning with respect to the evaluation of health infostructure initiatives and the benefits to be derived from them. Similarly, it will be important to ensure that all health infostructure projects and programs demonstrate the relationship of their proposed objectives and expenditures to the goal of improving or maintaining the health of Canadians. Finally, it will be vital to identify and meet any national needs that remain unaddressed by provincial and territorial health infostructure initiatives.

In conversations with stakeholders across the country, the Council has learned that without new money the present set of ambitious provincial and territorial health infostructure initiatives will suffer and new ones will disappear at the conceptual stage. For this reason, we believe that, in transferring funding for health purposes to provincial and territorial governments, the Government of Canada should work with provincial and territorial governments to ensure that a portion goes to development of their health infostructures, that they collaborate in developing the Canada Health **Info**way, and that their own plans and priorities are set within the context of a jointly developed Canadian health infostructure.

Preface

In the summer of 1997, the federal Minister of Health established the Advisory Council on Health Infostructure to give him strategic advice on the development of a national strategy for a Canadian health infostructure. The 24-member Council includes representatives from a wide range of stakeholders in the health sector.[1]

Mandate

The Council was asked to consider how information technologies and systems could best support and promote more informed decision making by health professionals, physicians, administrators, planners, policymakers and individual Canadians. The Council's focus was a client-centred health infostructure that meets the needs of the public, patients, informal caregivers, health care professionals and providers, and health researchers, managers and policymakers. Our work was not limited to health care. It also addressed the need to increase public understanding of broader, non-medical determinants of health.

The Council's mandate was to:

- develop a Canadian vision for a health infostructure and identify its basic shape and the essential needs it should meet;
- establish national priorities for improving the capabilities of a Canadian health infostructure to meet the needs of specific categories of users;
- identify and prioritize issues, challenges and barriers to the effective use of information technologies and systems in a Canadian health infostructure and recommend coordinated approaches and solutions;
- develop a long-term strategy to achieve a Canadian consensus for building a Canadian health infostructure;
- generate an agenda for action by all stakeholders to advance the implementation of the most vital components of a health infostructure;
- advise the federal Minister of Health on specific actions he might consider in moving this agenda forward; and
- advise on international developments in this area and take them into account when framing recommendations.

Although our primary mandate focused on health, we were also asked to examine the economic and industrial opportunities presented by development of a health infostructure. However, we ran out of time for a full exploration of these economic issues as well as international developments. Even so, if the recommendations in this report are acted upon, many economic and industrial opportunities will be created.

Process and Consultations

To carry out this mandate, we divided into working groups on vision and analytical framework, key policy issues, health information for the general public, and technology/applications. We discovered that the activities of these four working groups overlapped, encouraging useful debate and a cross-pollination of perspectives that advanced our work.

From the outset, we realized that a strategy for a Canadian health infostructure could succeed only through active collaboration and cooperation among federal, provincial and territorial governments, and among health professionals, administrators and policymakers, from non-governmental organizations and the private sector as well as governments. One of our central goals was to involve all these groups and organizations in discussing this strategy.

In February 1998, the Council took part in a National Conference on Health Info-Structure in Edmonton. Participants included 300 representatives of the public, stakeholders, industry and federal, provincial and territorial governments. The Council heard from representatives with a wide range of views on most of the key issues surrounding development of a Canadian health infostructure.

[1] Annex A contains a list of Council members and their backgrounds.

The Council also participated with the Canadian Institute for Health Information (CIHI) and Statistics Canada in interviewing some 500 health sector leaders about their information needs. Based on this work, Health Canada, Statistics Canada and CIHI recently developed a roadmap for health information for discussion by federal, provincial and territorial Deputy Ministers of Health in December 1998.

In addition, the Council's staff have been working actively with a recently established forum of chief information officers or their equivalents for federal, provincial and territorial health departments. Health Canada officials intend to continue this important work.

In October 1998, the Council's Working Group on Health Information for the General Public convened a two-day Key Informants Workshop, which brought together many representatives from national, regional and community health organizations. The resulting feedback strongly influenced the Working Group's recommendations.

On September 30, 1998, we released our interim report, *Connecting for Better Health: Strategic Issues,* and called for comments from all interested parties on our preliminary thinking and recommendations. The Council wants to thank all those Canadians, both individuals and organizations, who responded to our invitation. Your comments have been useful and insightful. In one form or another, many have found their way into our thinking and this final report. We have broadened our vision statement and strategic framework for the Canadian health infostructure in response to your comments. Many recommendations also reflect your thoughtful input in October and November 1998.

Next Steps

This final report contains the Council's considered strategy on how best to proceed in developing and implementing the Canadian health infostructure. Our job as an Advisory Council is now over. Our mandate is complete, although individual Council members will remain active proponents of the Canada Health **Info**way and its architects.

Critical to the success of the Council's strategy will be:

- the exercise of leadership by the federal government – and in particular, the federal Minister of Health and Health Canada – in building cooperation and collaboration among federal, provincial and territorial governments;
- the full participation of the general public as citizens, patients and caregivers;
- the active collaboration and cooperation of physicians and health care professionals and providers and their associations, as well as health managers, policymakers and researchers; and
- the involvement of non-government organizations and industry.

With our mandate completed, we pass to all these groups the task of building the Canada Health **Info**way for the benefit of all Canadians.

chapter one

Toward a Healthier Canada

Just as our health is a fundamental human right, so has access to Canada's publicly administered health care system become central to what it means to be Canadian. This report looks at how the strategic application of information and communications technology – through the building of a Canadian health infostructure or health information highway – can improve our own health and the quality and efficiency of health care across Canada.

This chapter defines a Health **Info**way or infostructure, describes the values that inform the Council's vision of the Canada Health **Info**way, sets out the strategic framework for building it, and underscores the critical importance of nation-wide cooperation and collaboration in its design and construction.

What Is the Canada Health **Info**way?

Although most people understand what "health" is, the notions of a "health infostructure" and "health information highway" are more problematic.

To be precise, an "infostructure" is a combination of the words "information" and "infrastructure" – in this case, a health information infrastructure. An infrastructure is a foundation on which to build. The main concern is information – its development, analysis, adaptation for different purposes, communication to appropriate users, and employment to improve health, health care and accountability throughout the health system.

However, equally fundamental is a capacity to provide improved communications – among the various players within the health system, among the general public and between both groups. The notion of a "health information highway" – or "Health **Info**way" for short – addresses the importance of effective communications as well as information to improve the health of Canadians.

In the Council's view, the Canada Health **Info**way will become the key information and communications foundation for our health care system and for improvements to the health of Canadians. Important new services will emerge that will build on capacities for communication over long distances and for creating, analysing and accessing information.

In this report, we will use the terms, "health infostructure" and "Health **Info**way" interchangeably. As noted in the Council's interim report, health infostructure or Health **Info**way has four key parts:

- *"the supporting technological framework,* including the cameras, scanners, telephones, fax machines, computers, switches, disks, video and audio platforms, cable wires, satellites, optical fibre, ..., etc.;
- *"the available information,* whether in the form of text, sound, images, data..., and the applications and software needed to access, manipulate, organize and digest it;
- *"the governance, management and use of information,* including standards to ensure...interconnectivity, reliability and security of systems and the physical and technological and legal means to protect the privacy, confidentiality and security of personal information; and

- "the people and organizations... creating the information, developing the applications and systems...and those using this infrastructure to deliver, maintain and improve health-related services for all Canadians."[2]

The Council agrees with this broad view of the Canada Health **Info**way.

"The power of computers has doubled at least every 18 months, while the capacity and affordability of communications systems have risen dramatically.... Distance and geography are now less of an obstacle to human interaction, including health care and the exchange of health information, than ever before."

The supporting technological framework is important. Over the last 25 years, the capabilities of information and communications systems have grown astonishingly. The power of computers has doubled at least every 18 months, while the capacity and affordability of communications systems have risen dramatically. And the two technologies have converged, producing powerful applications to create, analyse, transmit and use health information on a national, even global, basis. Distance and geography are now less of an obstacle to human interaction, including health care and the exchange of health information, than ever before. In short, these new technologies – some already developed, some being developed now as part of a health infostructure – promise to contribute significantly to improvements in health care and the health of Canadians.

However, as the definition above emphasizes, it is not technology but human needs and the requirements of the health care system that drive the Council's vision of the Canada Health **Info**way. Its policy framework is all important to ensuring that the infostructure truly meets these needs and requirements. This report is mostly about what such a policy framework should look like.

The Canada Health **Info**way will also not be simply one massive structure. It will be built upon the foundation provided by provincial, territorial and federal health infostructure initiatives already being designed or implemented. Each will retain its identity and integrity.

It is more useful to look for a definition of the Canada Health **Info**way in what we wish it to accomplish, as set out in the Council's strategic framework below. In addition, any definition will be temporary. Both the social and technological realities underlying the Health **Info**way are changing rapidly. As they transform, so too will our vision of it.

Values and Vision

The Council's interim report stated that the values supporting the Canada Health **Info**way should be the same values as those underpinning Canadians' support for a publicly administered health care system. The Council also stated it is the marriage of these values with a sense of new technological capability that provides the foundation for a vision of the Canadian health infostructure.

First and foremost, the Canada Health **Info**way should strengthen Medicare as a single-payer, publicly funded health care system guided by the five principles of the *Canada Health Act* – universality, accessibility, comprehensiveness, portability and public administration – within the framework of a strong federal/provincial/territorial partnership. As one of the commentators on our interim report emphasized, the values of fairness and compassion are the foundation of these principles and should influence development of the Canada Health **Info**way. Developing the Health **Info**way will involve collaboration with industry and health organizations within this context.

Privacy will be a key value in the Canada Health **Info**way. A fundamental condition for successful health care is the trust patients have that their personal health information will be protected. Otherwise, few would confide in a physician or health care provider. We believe that the level of privacy protection on the Canada Health **Info**way has the potential to be higher than in today's paper-based world.

[2] The Arlington Consulting Group, *The Canadian Health Infostructure: A Conceptual Overview* (Background Paper for the February 1998 National Conference on Health Infostructure), pp. 4, 5.

The Council believes that the Canada Health **Info**way should be inclusive rather than exclusive. Caregivers, patients, the general public, health care professionals, researchers, administrators and policymakers should participate as users and creators of the information. This information should be relevant, accurate, timely and appropriate to users – and in a format they can use. It will be critical to the success of the Canada Health **Info**way that users be involved in its design. A commentator on our interim report saw the need for "a spirit of cooperation and shared responsibility (ability to respond) between health care providers, the government, organizations providing health care and information, and the individuals using the health care system." We agree entirely.

The values of collective and personal responsibility identified by the Values Working Group of the National Forum on Health are particularly important. Canadians want to take greater responsibility for their own health. They want to participate meaningfully in decisions about health care policy. They would appreciate knowing more about opportunities to participate in the development of public policies affecting health and the health care system. Due to concern about the confusing complexity of today's health system, they also ask for equitable access and an efficient, cost-effective health system that will provide quality care in an accountable manner.[3]

The Council's vision flows very much from these values and concerns, just as it did in our interim report. However, we have modified our vision in light of comments on our interim report. Our vision is now more person-centred so that it revolves around both individuals and communities. We have made the fundamental concern with the value of privacy clearer. We also wanted to stress the enormous power of the infostructure to improve the accessibility, quality and integration of health care services. Finally, we wished to state more clearly the important contribution the Canada Health **Info**way can make to the system's accountability and cost-effectiveness, as well as our understanding of the broader health determinants.

In light of all this, our vision is as follows:

> *The Canada Health **Info**way empowers individuals and communities to make informed choices about their own health, the health of others and Canada's health system. In an environment of strengthened privacy protection, it builds on federal, provincial and territorial infostructures to improve the quality and accessibility of health care and to enable integrated health services delivery. It provides the information and services that are the foundation for accountability, continuous improvement to health care and better understanding of the determinants of Canadians' health.*

This vision is very people-focused. The individuals whom the Canada Health **Info**way should empower include individual Canadians, in their roles as patients, informal caregivers, citizens or consumers of health information; physicians, health care professionals and providers; and health researchers, managers and policymakers. The communities to be served by the Canada Health **Info**way range from local communities to Aboriginal communities to organizations to geographically dispersed "communities" that can be defined by a particular health concern. Our vision is about how the health of individuals and communities can be improved by the power of information and the growing capacity of modern communications to deliver services.

*"Privacy will be a key value in the Canada Health **Info**way. A fundamental condition for successful health care is the trust patients have that their personal health information will be protected.... We believe that the level of privacy protection on the Canada Health **Info**way has the potential to be higher than in today's paper-based world."*

[3] National Forum on Health, "Values Working Group Synthesis Report," *Canada Health Action: Building on the Legacy – Synthesis Reports and Issues Papers*, Vol. 2 (1997), pp. 6, 7.

Strategic Framework

The realities of the Canadian health system at the millennium have shaped our strategy for the Canada Health **Info**way.

As discussed in our interim report, the Council's strategic framework is based on a recognition that people are concerned about the health system, want to take more responsibility for their own health and want more accountability from the system. It stems from a realization that lack of coordination across the spectrum of health care services is a major source of inefficiency and public anxiety. It is based on the perception that health care professionals and providers need to keep up-to-date with the global explosion in health knowledge. Its foundation is a respect for provincial and territorial jurisdiction in health care delivery and federal jurisdiction in health protection, as well as a recognition that provincial and territorial health information systems represent the building blocks for the Canada Health **Info**way.

The Council has made important modifications to its strategic framework since our interim report was published. In our desire to focus attention on the value of health information to the general public, we had underplayed the importance of physicians, health care professionals and providers to the success of the strategy. In keeping with the importance of privacy as a key value, we have also reshaped our strategic framework to make privacy enhancement a key design feature of the Canada Health **Info**way. Our strategic framework follows.

The Canada Health **Info**way should:

1. Empower the general public by:
   - (a) providing reliable health information useful to Canadians as patients, informal caregivers and citizens;
   - (b) ensuring equitable access to health information; and
   - (c) offering opportunities for individuals and communities to hold dialogue on health care, engage in self-care and mutual aid, hold the system accountable, participate in health policy debates and provide input into health policy;
2. Strengthen and integrate health care services by:
   - (a) providing physicians, health care professionals and providers with communications and information tools, and the supporting environment, to improve quality, accessibility and efficiency within provincial and territorial boundaries; and
   - (b) enabling interprovincial health care applications and better portability;
3. Create the information resources for accountability and continuous feedback on factors affecting the health of Canadians to:
   - (a) provide new understandings of health determinants and the long-term impacts of health care interventions;
   - (b) improve management and cost-effectiveness within the health sector; and
   - (c) contribute to the sustainability of our publicly funded health care system by supporting better health policy formulation and analysis; and
4. Improve privacy protection within the health sector by:
   - (a) harmonizing provincial, territorial and federal legislative frameworks for the protection of privacy within the health sector; and
   - (b) implementing fair information practices and privacy-enhancing technologies by all organizations with access to personal health information.

The next four chapters will address these strategic goals. It is necessary to emphasize that right now it is only possible, as our mandate requires, to indicate the broad strategic directions and principles governing achievement of these goals. Construction of the Canada Health **Info**way is only in its very early stages. We cannot dot all the 'i's and cross all the 't's. Social and technological realities continue to change rapidly. These will affect profoundly how we go about implementing the Canada Health **Info**way. Most important of all, such an infostructure will have a positive effect on health and health care delivery so far reaching that its scope is now difficult to determine. This in itself may change the role of the infostructure.

Cooperation – The Critical Success Factor

European countries, Japan and the United States are all investing in information and communications technology applications for the health sector. In September 1998, the British government released a plan to spend more than £1 billion over seven years on such an initiative.

Canada's expenditures on information technology in the health field are expected to rise from less than $1 billion a year in 1996 to more than $1.5 billion by the year 2000.[4] However, there is as yet no overall strategy to guide how this money will be spent.

As noted in the Council's interim report, Canada has not one, but 12, interlinked single-payer, publicly funded health insurance systems. They are not in competition with each other, but many efforts to develop province-wide health information systems – the necessary building blocks for the Canada Health **Info**way – have occurred without sufficient consideration of how these will fit into a Canadian system in the future.

A Canadian strategy is needed to shape these developments. This strategy needs to fully reflect provincial and territorial needs and concerns, and respect their jurisdictional responsibilities with respect to health care delivery. It must also support the requirements of First Nations and Inuit communities to whom the federal government is transferring ever greater responsibility for health care delivery.

One of the federal government's roles is to encourage cooperation among the provinces and territories on matters of national importance. Whatever the outcome of ongoing discussions of a "social union" for Canada, this partnership approach will remain crucial to development of the Canada Health **Info**way. Disparities between provinces and territories in the resources available for building a health infostructure reinforce the importance of this federal role. Aboriginal communities face even greater resource constraints as well as pressing health needs.

The Council believes that the federal government has a responsibility to foster mutual cooperation and collaboration among provincial and territorial governments, Aboriginal communities and all stakeholders in developing and implementing our health infostructure. Otherwise, an important opportunity will be lost – to empower Canadians on health matters, to strengthen and integrate Canada's health care services, to improve management, policy making and research in the health sector, and to enhance privacy protection within the health sector.

Recommendation

1.1 The federal government has a responsibility to foster mutual cooperation and collaboration among provincial and territorial governments, Aboriginal communities and all stakeholders in developing and implementing the Canada Health **Info**way.

The first steps have already been taken. Federal, provincial and territorial chief information officers for health ministries now meet regularly to discuss cooperative approaches to health infostructure issues. As well, Health Canada, Statistics Canada and the Canadian Institute for Health Information (CIHI), an independent, non-profit organization, have released a roadmap to address Canada's health information needs. This roadmap is based on consultations with more than 500 Canadians representing health care professionals, providers and users across Canada.

[4] A.C. Nielsen and IDC Canada.

Key to Report

Chapter 1 has outlined the Council's vision and strategic framework for the Canada Health **Info**way. Chapter 2 indicates key measures that must be taken to ensure that the Canada Health **Info**way empowers the public. Chapter 3 lays out key elements of how the infostructure will help to strengthen and integrate health care services. Chapter 4 suggests the approach that should be taken to create the information resources for accountability and continuous feedback on factors affecting the health of Canadians. Chapter 5 indicates the broad directions to ensure that the Canada Health **Info**way improves privacy protection within the health sector.

Chapter 6 discusses some of the key steps that should be taken to ensure that the various parts of the Canada Health **Info**way can work together. Chapter 7 describes the building blocks for an Aboriginal Health Infostructure. Chapter 8 suggests approaches to making available the technology required to build the Canada Health **Info**way. Chapter 9 promotes the Canada Health **Info**way as a strategic infrastructure investment. Chapter 10 indicates who should carry on the Council's work.

chapter two

Empowering the Public

The Canada Health **Info**way should empower members of the public to make informed choices about their own health, their health care and about health policy. It should also encourage Canadians to become actively involved in the development of public policies governing the health system itself and other public policy areas known to affect health.

Several conditions must be met if the Canada Health **Info**way is to fulfil these objectives. First, its information content must match the needs and capacities of the public. Second, the public must have access to these new ways of conveying information. Third, the capacity for the public to participate in public policy development must be strengthened. But before examining the measures that must be taken to meet these conditions, we will take a broad look at how the Health **Info**way can provide means to empower the public.

A major issue in empowering the public is privacy. Thus, empowering the public needs to revolve around protecting the privacy – including the identities – of individuals requesting health information or visiting a website for that purpose. In the Council's view, everyone should have a right to privacy about their health information requests. Another issue is whether individuals should have access to their own medical records. In the Council's view, such a right exists in law and more should be done to actualize it.

Means of Empowerment

Repeated surveys over the last year have shown that health is the "number one" concern of Canadians – ahead of the economy, jobs, global financial instability and the environment. Many believe that the health system is in serious trouble after almost two decades of reform, restructuring and cutbacks. Some wonder how a health system which costs some $80 billion a year can seem so ineffective, and why there should apparently be long waits for some surgery procedures or radiation treatments. Some want to take action, but wonder how they can when all they have is questions, not answers. Most believe they are alone in their uncertainty and confusion. The Canada Health **Info**way promises to provide people with the means to organize electronically and get involved in health policy debates. This involvement will be informed because the infostructure will also make available a wealth of information on the health status of Canadians and the state of the health care system at all levels. These report cards will provide the basis for accountability to the public and meaningful input into health policy.

In today's complex health system, patients worry who can help them and what kinds of treatments might be best for their condition. More people find themselves acting as informal caregivers in the home and are asking the same questions and also wonder where they can go for support or respite. The Canada Health **Info**way should provide, not just over the Internet but over the phone or through direct contact, a wide range of reliable information in usable form. This should include local directories of health services, report cards on health programs and services, diagnostic aids, assessments of treatment options based on the empirical study of outcomes, analyses of drug effects and side-effects, and so on.

Living a healthy lifestyle used to mean getting some exercise, eating the right food and avoiding the usual vices. Now it seems we need a degree in sports medicine and nutrition to pick our way through all the expert advice about exercise programs, healthy diets, vitamin therapies and other treatments promising a healthy life. We can read media stories every day about some new allergenic, antibiotic-resistant bacteria, the carcinogenic effects of some food staple or the environmental hazards of another common household product. Finding out the truth is, of course, another matter. The Canada Health **Info**way will not disclose truth, but it will encourage the development and dissemination of much more empirically based information on the determinants of Canadians' health, including lifestyles, nutrition and social and economic policies. It will also provide clear pointers to credible sources of health information on lifestyles and nutrition.

Nothing is more fundamental than health. However, for centuries, members of the public have had to rely on the compassion and expertise of others to cure their illnesses and maintain their health. In today's complex, multi-billion-dollar publicly administered health care systems, the list of so-called experts has grown to include health managers, health policymakers, health researchers, health economists and media pundits, etc. Many of them disagree with each other and all claim to know far more than the public about its own health. No wonder more and more people express uneasiness at this "expertness" and want to find their own sources of reliable information as a basis for making healthy choices and holding the system accountable. The Canada Health **Info**way has the potential to give the general public the information it needs to make healthy choices and reach its own conclusions about the evolution of health care in Canada.

Health Information for the General Public

Observers of the health care system have long understood that the public generally has little say over how health services are provided and even less over how the system is organized and funded. It is also more widely understood, especially today, that the public's desire to exercise more control over its health could have very positive health payoffs. Ensuring that people have access to useful and reliable information is a powerful way to strengthen their sense of control over their own lives and support their desire to protect their own health. Such access can also encourage them to become directly involved in developing public policy. New ground rules to provide information to the public could create a new voice within the system – one pushing for greater accountability and more say over how health care resources are allocated.

An essential public good

The Canada Health **Info**way has the potential to empower the public in several ways. It can provide information useful in understanding and managing specific health conditions, including information about self-care strategies. It can encourage more informed decisions by providing reviews of the latest scientific research evidence on the pros and cons of various treatment options. It can assist in finding appropriate, locally available services. It can provide the public with new educational opportunities – such as on-line courses that teach critical appraisal skills in assessing research evidence.

The Health **Info**way can also provide people with broad general information about the most important social, economic and environmental influences on health. This analysis could help inform the public about the likely "health" impacts of various public policy proposals. It can establish new ways for holding the system accountable for the quality of care provided – for example, by publishing report cards on specific performance measures. It can further steer the public to helpful interactive resources such as chat groups, news groups, bulletin boards and list-servs that help people connect with others who have common interests. These resources also provide more immediate and individually tailored information than can be obtained through books and articles. Evidence also suggests that they offer much needed support for those coping with health problems.

It is important to understand that the provision of relevant information on-line is not just a one-way street – with all of it coming from professionals. Lay members of the public have their own insights to contribute. These have already proven useful to clinicians who are active users of these on-line resources. More and more health professionals are communicating with their patients via e-mail and finding that it improves their relationships with patients. These new communications seem to foster more equal partnerships – the professional becomes more a coach, a consultant or a facilitator than a final authority.

Making health information available to the public is an essential public good with enormous and positive implications for transforming Canada's health care system. Particularly in a publicly funded system within a democratic society, the availability of such information is also rapidly becoming integral to health care and critical to holding the system accountable. In funding decisions for the Canada Health **Info**way, making such information available to the public should be a key component of our publicly funded health system.

Health Information for the General Public should include:

- general health information, including health promotion information and information on healthy lifestyles and health maintenance;
- health care information, including information on treatment options, drugs and pharmaceutical products, and managing illnesses or health conditions (e.g. high blood pressure, diabetes or obesity);
- information on public health issues, such as the quality of air, water and food;
- accountability data or report cards on, for example, the performance of health care services and providers;
- health policies at the federal, provincial and territorial levels, as well as information on health policies in other countries and policy research papers;
- data on health impacts of policies for areas other than health; and
- information on the effects of health determinants.

Recommendation

2.1 Health Canada, in partnership with provincial and territorial ministries of health, should recognize in its funding decisions for a health infostructure that health information is an essential public good which should be readily available and accessible to all Canadians as a component of Canada's publicly funded health system.

A Complex Challenge

Information can be a source of power and support. However, it is not often the most important factor influencing behaviour. If we are to improve the chance of good information leading to healthy behaviour in personal and policy terms, it will be important to recognize that the general public's health information needs will be very complex. For one thing, there is no such thing as a "general public" when it comes to health information needs. Information must be tailored to individual users or specific groups of users and to people's differing needs for information over time.

Searching the Web for breast cancer information – a scenario for the near future

After being diagnosed with breast cancer and advised to undergo surgery, Suzanne tells her friends she needs more information to better understand her condition and all of the treatment options open to her. She searches the Internet for reliable sources of information about breast cancer, its treatment and the alternatives she faces. Through the Internet, she also finds support groups for women with breast cancer; she then gets in touch with Lise, a woman who has faced the same situation. Suzanne is able to share her experiences with Lise, who also tells her about a website that provides report cards and assessments on treatment options for her cancer. Suzanne checks it out. After gathering all this information, discussing it with her physician, and talking over her situation with her family and members of the support group, Suzanne is able to make an informed decision.

Changing individual and family circumstances will create different needs for health information. Information perceived as irrelevant yesterday may be vital tomorrow. The ability to process information also varies with time. For example, most people who have received a cancer diagnosis will admit difficulty recalling what they were told immediately afterwards. Later, their thirst for information about their condition and the options facing them can be overwhelming.

It is usually a family or personal illness beyond self-care solutions that gets people interested in health information. People generally seek professional advice either in person or by phone to identify the source of the problem and to receive a recommendation for treatment. If the solution is straightforward, there may be no need for additional information – apart from advice about how to avoid future recurrences, if solutions for prevention exist. If the solution is not so simple or if people want information to make healthy lifestyle choices, they may consult other more general sources of health information – for example, the media or school health programs. But these may not target the specific needs of many individuals and may not be useful.

As already noted, the Internet and the Canada Health **Info**way have the potential to provide more individually tailored forms of information. However, there are already hints of public discontent with some kinds of health information available on the Internet. For example, veteran users tend to dismiss the more traditional "patient education pamphlets" as "shovelware" with very limited usefulness. While the best of these materials may be helpful to new users, more experienced users express a growing preference for more interactive health information exchanges that respond to individual circumstances. This situation suggests that merely taking print-based materials and posting them on a website or list-serv will fall seriously short of public expectations.

When testing and developing health information for the public, it will be critical to recognize that people's health information needs differ greatly, depending upon background, situation and condition. Health information must be relevant and usable to people with different cultures and languages, levels of education, income levels, health concerns, disability levels, cognitive abilities and ability to use or access information technology. Some will be patients experiencing stress and fear. To say information and its delivery must be user-friendly is only to scratch the surface. The information must be developed with the needs of each of these diverse groupings in mind. As the Canadian Nurses Association emphasized in its comments on our interim report, "The infostructure should support individuals in the way they choose to relate to the health system."

In many cases, public access to a range of health information databases, however perfectly indexed, will be insufficient for many Canadians and would be a poor replacement for a major source of support. That source of support is the many intermediaries on whom the public relies extensively to meet its health information needs. In addition to family, friends, teachers and health care professionals, people commonly ask intermediaries – libraries, consumer groups, health information centres and non-profit groups or voluntary organizations – for advice in finding or interpreting health information. People may need help in understanding the issue, searching for relevant information or determining whether and how information applies to their particular situation.

For example, consumer organizations play a large role in helping people find the health information they need. They will be an important source of advice to the developing health infostructure about the types of information required. These health intermediaries have a long record of expertise and responsiveness to particular segments of the public. The activities of these organizations and groups deserve support.

Many patients and informal caregivers may also need personal contact, at any hour of the day or night, with knowledgeable, sensitive people who can provide reassurance and answers to questions. In Canada, Quebec's Info-Santé represents an ideal example of such a service. It is now moving onto the Internet and discussions are under way to make similar services available in other provinces.

People may also want health information, not to resolve some personal or family health concern, but to hold the health care system accountable. For example, many citizens serve on the boards of regional health authorities, hospitals or community health centres. They may need extensive health system information to plan programs and allocate resources.

It should be emphasized that these groupings are not distinct. Patients coping with personal health problems become motivated to join support groups and other types of consumer health organizations. Some will join health advocacy groups trying to make the system work better. Within each grouping, health information needs will also continue to change and grow over time. This reality suggests that the Health Infoway will require a long period of development and its successful evolution will involve ongoing testing of assumptions about how people actually use and value its offerings. Health Canada should carry out, in partnership with other levels of government and health stakeholders, an investigation of the health information needs of the general public, using a variety of culturally and linguistically appropriate strategies.

> Info-Santé enables Quebeckers with a health concern to contact skilled nurses by telephone 24 hours a day, seven days a week, from anywhere in the province. The service, established in 1995, is one of a set of measures intended to reduce use of hospital emergency wards. Info-Santé aims at helping individuals and families take charge of their own health and helping them obtain the necessary assistance from the most appropriate sources. In 1997-98, the service received 2.4 million calls. In 95% of calls, users said the call helped them find a solution. Data from evaluations of Info-Santé indicate that every 100 calls to the service prevent 29 inappropriate trips to emergency.

Many Canadians also lack the digital and search skills needed to make effective use of the kinds of health information that is increasingly available over the Internet. Health Canada will have to address these gaps, in partnership with other federal departments, other levels of government and the many consumer health intermediaries which have been major sources of health information to the general public. A key resource in these efforts will be the Canada Institute for Scientific and Technical Information (CISTI), which has a long-standing mandate to be active in the health information area. There will be a need to fund demonstration projects to show how the level of access to consumer health information can be improved. As well, it will be necessary to support with funding the efforts of consumer and health intermediaries to develop and provide access to consumer health information.

Health Canada's Canadian Health Network (CHN) represents a significant first step toward meeting many of the general public's health information needs. It provides people with a single window – including a multilayered website – on timely and credible consumer health information. The goal is to create an integrated health information service managed and sustained by many partners, including provinces and territories. This initiative deserves support.

Recommendation

2.2 To understand better the information needs of the public, strengthen people's ability to access and use evidence-based information, and provide mechanisms for public access to reliable health information, Health Canada should:

(a) undertake, in partnership with other levels of government and health stakeholders, an investigation of the health information needs of the general public, using a variety of culturally and linguistically appropriate, interactive and ongoing strategies;

(b) promote, in partnership with other federal departments and agencies (e.g. the Canada Institute for Scientific and Technical Information) and provincial and territorial departments and agencies, the ability of Canadians to access and use evidence-based, non-identifiable health information to meet their health information needs and concerns by establishing a fund that will support demonstration projects;

(c) establish a fund to allow consumer and health intermediaries to develop and provide access to consumer health information; and

(d) support the Canadian Health Network as one mechanism for providing Canadians with access to reliable health information.

Standards for Health Information

Canadians need to be able to trust the health information they receive through the Canada Health **Info**way. Several questions are relevant to this question of trust. For example, what kind of evidence supports the information? Is the source of the information authoritative? Is the information produced to educate and inform or to promote a product or service?

More complicated issues of trust emerge when one considers the differences among people – including scientists and health care professionals – on health issues. A wide assortment of conflicting opinion, analysis and viewpoints exists on many health questions. For example, some believe in the effectiveness of alternative medicine; others reject it in favour of conventional medicine. How can the public assess the reliability of such information? What kind of guidance would help them verify the quality of information available through the Health **Info**way?

The ways people learn can also affect how they process information. For example, some may find a personal testimonial to a product or service far more comprehensible and convincing than a review of extensive, carefully controlled clinical trials.

Many of these issues could have potentially serious implications. For example, what happens if inaccurate information obtained through the infostructure results in harm to a member of the public. Is there a legal basis for a lawsuit? Are disclaimers sufficient to prevent legal action?

At the February 1998 National Conference on Health Info-Structure in Edmonton, there was consensus that national leadership was required to provide guidance to consumers about the quality of information available through the health infostructure, including the development of a rating procedure to identify "recommended" sites for health information. As the Ontario Prevention Clearinghouse pointed out in its comments on our interim report, "Consumer information must be transparent as to its source, credibility and ownership. Consumers value standards, relevance and responsiveness, and attribute confidence to information which has the support of Canada's non-governmental organizations and governmental organizations...." In the Council's view, Health Canada, in partnership with provincial and territorial ministries

of health, should take the lead in ensuring development of standards or guidelines to distinguish between objective, evidence-based health information and information intended to promote a product. These guidelines could be developed into criteria for rating websites that provide health information.

Recommendation

2.3 Health Canada, in partnership with provincial and territorial health ministries, should take the lead to:

(a) ensure that standards/benchmarks/guidelines are developed and implemented to allow the general public to distinguish objective, empirically based health information from information intended to promote a product; and

(b) expand these standards/benchmarks/guidelines eventually to include rating criteria for websites providing health information.

Commercial activity on the Internet and World Wide Web poses more challenges. Products and services are being advertised and sold in an electronic environment currently not subject to the kinds of regulatory controls that exist in more traditional marketplaces. For example, drugs not approved for sale in Canada can be ordered from other places with less stringent regulations. This availability raises health and safety issues. Federal, provincial and territorial governments are working to develop a legislative and regulatory framework for electronic commerce on the Internet. However, special considerations are required for commerce in health information and health products to protect consumers adequately.

Recommendation

2.4 Health Canada should work with other health stakeholders to:

(a) ensure that health concerns such as consumer protection with respect to health products and services are adequately reflected in the present work of federal, provincial and territorial governments to develop legislative and regulatory frameworks for electronic commerce on the Internet; and

(b) take appropriate alternative action if health and safety issues are not adequately reflected in this work.

Removing Barriers

Canada is an officially bilingual country, but the Internet has much less French- than English-language information on health and other subjects. Existing search tools on the Internet will not specifically seek out health information in French. However, Canada is a world leader in the development of multilingual search software. In the Council's view, it will be necessary for government to take steps to encourage the development of an Internet search capability for health information in French.

Recommendation

2.5 Health Canada should work with other federal departments and agencies and specialists in the field to encourage development of:

(a) an Internet search capability which is specific to health and, at a minimum, fully and equally meets the needs of Canada's English- and French-speaking communities; and

(b) Internet content on health in French and English.

Other linguistic groups, particularly Aboriginal groups, also have difficulties finding health information in their traditional languages. In some Canadian jurisdictions, these are recognized as official languages. Equity demands that governments take a role in ensuring that these linguistic needs are met.

Part of the solution with respect to French and other languages may lie eventually in developing technologies for automatic translation, in which Canada is an acknowledged world leader.

Publicly funded, federal government collections and databases already contain a wide array of health information which would be useful to members of the public, to assess their own health situation and the performance of the health care system. However, policies and procedures to recover the costs of collecting and creating this information and to bring in revenue have made this information too expensive for many people. Even the non-profit organizations representing these people find the costs too high. Given the fundamental importance of reliable health information to empower people in the field of health, it is inconsistent that people should be charged extremely high rates for access to public collections and databases. In the Council's view, the policies and practices creating this situation should be reviewed.

Recommendation

2.6 Health Canada, in partnership with representatives of user communities such as the Canadian Association of Public Data Users, should take the lead in approaching Treasury Board and other federal departments and agencies to review the policies and practices with respect to cost recovery and revenue generation governing the availability and redistribution of publicly funded collections, statistical databases and other government information relevant to health.

Ensuring Access

It is vital that there be affordable, equitable access throughout Canadian society to the Canada Health **Info**way.

Policies to encourage access should consider factors such as geographic location, cognitive ability, language, physical disability, cultural origin, educational background, age, gender, income, social differences, technophobia, and traditional and digital literacy. They should also consider the stress many patients and caregivers face in seeking information and support. Access policies must focus not just on delivery technologies but on the format, level of difficulty, language and ethnocultural assumptions that will determine the usefulness and acceptability of information for different groups.

Access objectives are easier to achieve because of the rapid advances in communications and computer technology over the last 30 years. These promise a growing capacity to overcome traditional barriers of distance and geography. These will also provide all Canadians with better health information and opportunities to participate in formulating and implementing health policy. The most visible example of this technological revolution is the Internet. The Internet is rapidly entering Canadian homes and provides a unique tool to exchange information and connect communities of like interest across the country.

However, according to Statistics Canada, only 29.3% of Canadian households had in October 1997 at least one member who typically used a computer to communicate every month at home, work or another location. A range of characteristics, including lower income and educational attainment, relate to lower use of the Internet. Any access policy relying exclusively on the Internet must address the disadvantages faced by these groups.

Other obstacles to access may be equally serious. For example, patients and informal caregivers may be under stress when seeking information and may need direct contact with someone to help them through a difficult situation.

Multiple modes of accessing many different sources of health information will be critical to ensuring that the Canada Health **Info**way actually does empower the public. Modes of access could include not just the Internet, but also phones, faxing traditional hard copy and direct contact with sensitive, knowledgeable staff. It is clearly important for governments to strike a balance in their mechanisms of communication.

Recommendation

2.7 Investments in the digital networking of the Canada Health **Info**way should be balanced by appropriate investments in the other (i.e. non-electronic) mechanisms for sharing information that can lead to improved health.

Although the speed, reach and cost of a particular technology will always be important, how the information is presented, the language used and the ethnocultural assumptions underlying the information can all present total barriers to use by many Canadians. Equity demands the removal of such barriers.

Access policies will also have to acknowledge the importance of user friendliness in technology and the public's need for instruction in its use. For reasons of equity, such policies must take into account the different needs of women and the particular challenges facing people with disabilities, too low an income, a language other than English or French, or low levels of literacy.

The Information Highway Advisory Council (IHAC) in its 1995 report, *Connection Community Content: The Challenge of the Information Highway*, saw "universal, affordable and equitable access" as the first principle that should govern policies for access to facilities and services on the Information Highway. IHAC saw this principle as involving "...local availability of basic access facilities for the delivery of Information Highway services at reasonable cost, regardless of geographical location; equitable opportunity for all, including people with disabilities and groups with special needs, to access and use the Information Highway."

The Council strongly agrees with this principle. Like IHAC, we believe that this principle means that, for basic telecommunications infrastructure such as the telephone network, the government should ensure that every household continues to have access to it. For new kinds of networks such as the Internet, this means that access should be possible in every community and neighbourhood, either at a local library, health facility or some other public site, on an affordable, equitable and sustainable basis. In future, if the Internet evolves into a basic network comparable to the telephone today, the government may have a role in ensuring that it is as widespread in households as the telephone is now.

Recommendation

2.8 To ensure that health information is accessible on a universal, equitable and affordable basis, it is vital that:

(a) the federal government continue to ensure universal, equitable and affordable access to existing and future basic telecommunications infrastructure; and

(b) Health Canada, in partnership with provincial and territorial ministries of health, take a leadership role in ensuring that health information and health care applications for the general public are developed in such a way as to be accessible to all citizens, irrespective of their geographic location, income, language, disability, gender, age, cultural background or level of traditional or digital literacy.

An important source of access to health information will be the many community networks and freenets in municipalities across Canada, especially in urban areas. These provide non-profit, community-controlled "electronic public spaces" as avenues for citizen participation and community development.

Government policies and regulations have long recognized the importance of such "public spaces." Since the 1970s, Canadian cable companies have been expected to make community cable channels available to non-profit groups and institutions in their localities.

In the Council's view, there is a real need to establish a "Canada Health Space." This would be a universally accessible health information/communications commons owned by Canadians and operated in the public interest. The Canada Health Space would be a place where Canadians can communicate and share information and experiences. In it, every individual or organization with products or activities affecting health would report on their health implications. The Canada Health Space would be operated by health intermediaries – libraries, community health information centres, clinics, health promotion organizations, etc. – which represent major sources of health information for many members of the public. The key role of the intermediary is apparent in this description of a librarian's function by an individual commenting on our interim report, "Librarians have the knowledge skills to evaluate, collect and retrieve appropriate material; and the people skills to facilitate equitable access and interpretation over a wide range of abilities."

The ***Western Health Information Project*** (http://ycn.library.ns.ca/hosp/health.htm) is a collaboration by local hospital and public libraries, Yarmouth Community Net and a school of nursing program which supports consumer and wellness information for the community. This Internet-based project includes access to locally developed consumer health information, a directory of local health agencies, links to health-related websites and access to the Infotrac Health Reference Centre database. It complements and links with existing library collections.

The networking of these organizations represents a real opportunity for Health Canada to fulfil its own statutory responsibility to inform the public. Already, many of these organizations assist Health Canada in its health promotion activities. They will be much more effective if they can share information and link together in serving the public, thereby providing access to a much wider range of information. For these reasons, the networking of these health intermediaries deserves support, including adequate funding and technical support for their efforts to provide the public with quality health information.

One source of support for these efforts could be government's own determination to provide more of its own information and services electronically. As the Information Highway Advisory Council pointed out in its 1997 report, *Preparing Canada for a Digital World*, this move to electronic modes of delivery shifts distribution costs to the citizen, including the non-profit community networks and freenets that provide significant citizen access to government information and services. The Council believes that government should consider ways of supporting community networks which deliver government services and information, as was recommended by the Information Highway Advisory Council in 1997. Such compensation should be regarded as a normal cost of doing business.

Recommendation

2.9 Health Canada, in partnership with other federal departments, provinces and territories, and health stakeholders, should:

(a) ensure establishment of a "Canada Health Space" as a universally accessible health information/communications commons;

(b) capitalize on and support the nation-wide networking of health intermediaries;

(c) ensure adequate funding and technical support to health intermediaries to develop and/or maintain their capacity to provide the general public with timely, credible and "understandable" health information and to assist in overcoming access barriers; and

(d) accept, as a normal budgeted cost of doing business electronically, the need to sustain health intermediaries and support them for providing affordable electronic health information services to disseminate health promotion, health protection and other kinds of health information to wider publics, just as such costs have been accepted in the paper-based world in the past.

Much has already been accomplished through the federal government's connectedness agenda in removing technological obstacles to access. The Community Access Program (CAP), SchoolNet and First Nations SchoolNet – all partnership efforts by Industry Canada, provincial and territorial governments, communities and the private sector – are now connecting all Canada's schools and libraries to the Internet. First Nations SchoolNet has already linked all interested schools in First Nations communities by means of a direct personal computer satellite service that provides high-speed access to Internet-based material. By the year 2001, CAP will have created 10 000 public access sites in rural/remote communities and urban neighbourhoods. In 1997, Industry Canada set in motion a three-year program to offer connectivity to 10 000 charitable and selected non-profit organizations – including health organizations. Health Canada, in partnership with provincial and territorial health ministries, should work closely with Industry Canada to make public and not-for-profit health care institutions aware of these programs.

Recommendation

2.10 Health Canada, in partnership with provincial and territorial ministries of health, should work closely with Industry Canada to ensure that all public and not-for-profit health care institutions in Canada are aware of:

(a) the Community Access Program; and

(b) how they can apply for resources to locate public electronic access facilities on or near their premises to help ensure that their clients can use on-line health information.

The Arthritis Society of Canada has established an encyclopedic, interactive website (www.arthritis.ca) to try to meet the needs of Canada's arthritis community. Content in both official languages includes articles on types of arthritis, medications, pain management, surgery, everyday living strategies, exercises and much more. The site receives an average of 15 000 "hits" daily. Since many Canadians still do not have direct access to the Internet, The Arthritis Society's 800 information line links them to the website's vast inventory of educational information. Callers anywhere in Canada dial a single number and are automatically routed to the Society provincial office closest to the caller's area code. Trained telephone volunteers – many of whom have arthritis – respond to public queries by downloading pertinent information from the site for direct discussion with callers or for distribution via fax or mail.

Because communications and computer technology is evolving so quickly, it will be a continuing challenge to ensure the health sector keeps up-to-date. In many areas, we are still at the research stage of learning how to integrate these technologies into health networks or use them to improve access to health services and information. For example, satellite technology may have potential to help improve access to health services the federal government is responsible for – such as health care services in First Nations communities. Both Health Canada and provincial and territorial health ministries should work with sources of technological expertise such as Industry Canada and the Canadian Network for the Advancement of Research, Industry and Education (CANARIE) to explore further integration of new technologies into health networks.

Recommendation

2.11 As a means of ensuring more equitable access to health information and health care services, Health Canada, in partnership with provincial and territorial health ministries, should work closely with the Canadian Network for the Advancement of Research, Industry and Education, and Industry Canada to investigate the further integration of new technologies, including satellite technologies, into health networks at all levels.

Public Input and Accountability – Promoting Citizen Engagement

The Internet is now connecting communities with like interests, independent of distance and at very low cost. It allows people to exchange information electronically, share concerns, develop common positions and take collective action on issues, whether at the local, provincial, territorial, national or international levels. This process enables the public to provide effective input to policymakers and hold them accountable. Taking advantage of the Canada Health **Info**way to generate policy research data and improve the data's availability should also help to ensure more informed public input on health policy.

"It is important for the National Health Service to grasp the extent to which the public wants access to comparative clinical outcome information relating to local National Health Service facilities. Despite the acknowledged difficulties in ensuring fair comparisons, the arguments for tackling these difficulties and making such information available are irresistible."

Information for Health:
An Information Strategy
for the Modern National Health Service
London, England, September 1998

In addition to demonstrating a commitment to democracy and giving citizens a renewed sense of ownership in and commitment to public institutions and processes, there are other reasons for policymakers to seek input from consumers. When designing consumer-sensitive programs and services, policymakers can benefit significantly from consumers' unique information about their experiences with the health care system. They can also often bring fresh perspectives to the traditional policy debates between funders and health care providers.

Federal, provincial and territorial health ministries frequently ask for stakeholder input on policy changes, including input from the public. Generally, these consultations work with established groups and organizations as well as professional associations. Most observers agree that the consumer voice in health care is relatively weak.

In recent years, many of the large national consumer organizations have had to cut back their activities because of constrained resources. The smaller number of community-based consumer groups are too fragmented and individually too small to exercise much influence over policy. Most are voluntary organizations largely dependent on volunteers' time, energy and financial resources.

The public is also diverse. People with disabilities, seniors and women, for example, will each have a unique view on the shaping of health policy, the Canada Health **Info**way and the information it carries. Typically, people who become involved are patients or relatives of patients who have concerns about how the system meets or fails to meet their needs. Some groups aim at filling an important gap in service – say, providing information and mutual support to people coping with, for example, mental illness, AIDS or endometriosis. Others believe they have been harmed by medical treatments such as blood products or breast implants. Still others focus on larger groups such as women and seniors. The latter will often address not just health care but areas such as housing, income support, child care and the environment which have effects on health.

In the Council's view, it is necessary to establish ongoing mechanisms to carry out policy research and to formulate health policy options. As a result of a recommendation by the National Forum on Health, the Canadian Institute for Health Information (CIHI) has recently begun a Canadian Population Health Initiative to do some of this work. When the steps for action in the report *Health Information Roadmap: Responding to Needs* are implemented (see Chapter 4), CIHI and others will be in a stronger position to do research and analysis as a basis for report cards to the public on national health status and the performance of the health system.

The Council believes there is also a need for an independent office to take on a policy advocacy role, to involve and link together these diverse publics and allow them to express their concerns about health policy and the health system as a whole. This office could be a virtual or a physical organization.

Recommendation

2.12 Health Canada should establish a non-governmental office of citizen health advocacy to coordinate and facilitate input and participation by the general public into health policy deliberations, including policies relating to the Canada Health Infoway. This office would:

(a) coordinate and facilitate the linking of community-based voluntary health organizations and health consumer organizations to enable or enhance their capacity to participate effectively in health and public policy development; and

(b) constitute an ongoing, stable mechanism for obtaining reliable and representative input and feedback from the health consumer sector.

A possible model for this office is the Consumers' Health Forum in Australia. It was established in 1987 in response to petitions from consumer and community groups that wanted to have more influence on health policy. The Forum does not duplicate the work of existing organizations. It takes on issues the entire consumer health movement wishes to act on together. Its membership is restricted to organizations directly accountable to consumers. Whatever model is used for a Canadian office of citizen health advocacy, it will be crucial that Health Canada proceed sensitively to ensure that the consumer health community can take ownership of the organization and feel that it responds to consumer health needs.

A key role of this office would be to ensure production of assessments and evaluations of the health system that are relevant and accessible to the general public. These could help set the agenda for, and serve as the basis for critiques of, the report cards prepared by CIHI and perhaps others in collaboration with provincial governments. These report cards would detail the performance of health care organizations, the outcomes of interventions and the actual health impacts of health policies and policies for other areas (see Chapter 4).

Recommendation

2.13 The office of citizen health advocacy should ensure production of assessments and evaluations of health sector activities relating to the general public. These would include setting agenda and critiques for report cards on the performance of health care programs and services, outcomes of interventions and treatments, and the actual health impact of health policies *(See also Recommendation 4.2).*

chapter three

Strengthening and Integrating Health Care Services

In addition to strengthening health care by encouraging a more informed and involved public, the Canada Health **Info**way will directly contribute to significant improvements in health care services. Its essential building blocks, the provincial and territorial infostructures, will help lay the foundation for great improvement in integrating and coordinating health care services within each province or territory. Further enhancements will occur as the infostructure takes on a pan-Canadian dimension.

This chapter looks at the key steps that must be taken to transform this promise into reality. It also examines some of the potential practical contributions the infostructure can make to health care services. Vital to success will be measures to ensure that health care professionals and providers can use these new communications and information tools to improve the quality, accessibility and efficiency of health care services. Some of these tools are far from fully integrated into the present health system. Telehealth, an application important to achieving these improvements to health care services, still faces barriers which will have to be overcome. Another crucial application is the electronic health record which will need to be implemented in a manner that fully protects personal privacy.

Health Care and the Canada Health **Info**way

The provincial and territorial health infostructures of the Canada Health **Info**way have the potential to contribute to improving health care services, including public health services.

Currently, health care services are organized like a series of silos – with one silo for primary care, another for acute care, a third for ambulatory care, a fourth for home care, and yet another for long-term care. This approach works well – as long as patients do not move from one silo to another or if no one cares what it adds up to in terms of effective and efficient patient care. In the real world, of course, we care very much and everyone knows that in a normal recovery a patient will move from one silo or kind of service to another. In the present situation, continuity of care is difficult to achieve and it is all too easy for a patient to slip between the cracks or enter a new silo with no record of his or her previous treatment. As the Canadian Pharmacists Association pointed out in its comments on our interim report, "It is common for changes to a patient's medication regimen made in hospital to be reversed or ignored when that patient moves back into the community, simply because

the information does not reach the primary care physician." Although full integration of health care service delivery involves serious commitment at all levels, the Canada Health Infoway promises to make it much easier for a patient to move in a fully supported fashion from one care setting to another. Telehealth applications will allow health care professionals and providers to remain in close communication with each other and exchange information efficiently, even though each may work in a different setting. The development of an electronic health record will allow patients to ensure access – subject to stringent privacy safeguards, confidentiality obligations and security practices – to their medical histories by health care professionals and providers in different care settings.

The health of many people, particularly elderly persons, fares better in their homes outside an institutional setting, but only if the right sorts of social supports and levels of care are available in the home. Home care services are not now evenly available across the country. Even within particular provinces and territories, many people cannot get the home care they need and deserve. This problem will only grow worse as the population ages. The Canada Health **Info**way can, through applications such as tele-homecare, help provide important opportunities for improvement and innovation in home care. According to the Canadian Home Care Association in its comments on our interim report, "the potential of video and audio links and technologies such as telehealth will enable providers to deliver home care services very differently in the future, and likely in a much more effective and efficient way. Providers will be able to monitor and assess clients without a physical visit in some cases, and, when in the home, providers can access specialists and other members of the care team through the technology of video recorders, computers and modems. Individuals will receive care in less intrusive ways, yet still be closely connected with their providers and the specialized expertise when required. These advances can only help to improve the health of Canadians...."

Access to care in rural and remote areas poses a continuing challenge to the Canadian health care system. Health care professionals and providers in rural and remote areas often have to make difficult decisions on their own. They may also lack access to urban facilities for training and upgrading skills, with the result that many return to the city. Patients must often make expensive trips to the city to receive specialized diagnoses and treatment. Through telehealth applications, the Canada Health Infoway has the potential to support diagnosis and even treatment of patients in rural and remote communities by specialists based in cities. The same technologies can ensure that health care professionals and providers receive expert support when making difficult decisions, while opening up new opportunities for training to maintain and upgrade their skills.

"The continually changing and expanding body of medical information is increasingly difficult to master. In 1985, Covell and colleagues documented the obstacles physicians face using books and print media as sources of information in practice. Thirteen years later, there are 9.1 million MEDLINE citations with approximately 31,000 more added each month. Combined with the psychological, sociological, and administrative complexities of medical practice, this rapid proliferation of information pressures physicians to make decisions at the margin of what they remember and know. Compounding this problem, changes in health care delivery require practitioners to make more important and complex decisions in less time. Physicians' trouble in applying current health care evidence effectively will almost certainly worsen given these trends. Weed calls this failure to use current health care evidence in the practice of medicine 'avoidable ignorance'."

"Medical Information on the Internet," Editorial, Journal of the American Medical Association, October 21, 1998

Supporting the Health Care Team

The professionals and providers who actually deliver care are central to health care. Without their active support and use of the new tools offered by the Canada Health **Info**way or its provincial and territorial counterparts, little will change and evidence-based decision making will remain more a promise than a reality.

Health care is an information and communication-intensive activity. Indeed, as noted in Chapter 1, because the amount of specialized information for health professionals is growing so fast, it has been estimated that practitioners would have to read 19 articles a day, 365 days a year, in order to keep up-to-date. This reality may explain why, according to a 1998 Canadian Medical Association (CMA) survey, physicians are rushing to embrace the Internet. Between 1997 and 1998, the proportion of physicians using it grew from 41% to 56%. More than half now use e-mail regularly, up from 37% in 1997. Of the physicians accessing clinical practice guidelines through the CMA's database-search services, 49% said these guidelines had changed the way they practise.

For such services to encourage evidence-based decision making, the health care information made available must be timely, accurate, accessible and user-friendly. Equally important, health care professionals and providers across the entire spectrum of health care must be encouraged through incentives to carry out their responsibilities in these new ways. The question of incentives is all-important because many professionals and providers are wary of the new technology or see little reason to change their ways.

As an administrator from one regional health authority put it when commenting on our interim report, "Primary care is a vital part of the infostructure equation. Technology adoption is a significant barrier when attempting to integrate information with this group. I believe more incentives need to be offered via the provincial and federal governments to encourage the primary care group to become active participants."

The kinds of incentives that should be made available will require careful consideration. They should respond to the real needs of the physician and health care professional and provider community.

Recommendation

3.1 Federal, provincial and territorial governments should develop and test incentives to encourage and assist health care professionals and providers to adopt health infostructure applications. These applications include clinical decision support tools, health information systems and telehealth.

Most health care professionals and providers will also need training in how to use these new information and communications tools. In addition, the greater the range of health care professionals and providers involved in testing such tools, the more likely they are to be useful and user-friendly and that people will actually use them. A communications professor saw a need for "participatory design processes... where those working with health information technologies (e.g. nurses, doctors, administrators, health researchers) assume an active role in the development of health information technologies." Governments, in collaboration with associations of health care professionals and providers, should take an active role in ensuring that these opportunities for training and testing of new applications exist.

> "Today, family physicians are key recorders and managers of personal health information.... It is our opinion that some of the most critical collaboration required for the fulfilment of the Council's vision re health infostructure are those with front-line family physicians and their representative organizations. It is our sense that there has been little by way of candid acknowledgement of the importance of such collaborations in the past."
>
> ***College of Family Physicians of Canada, commenting on the Council's interim report***

Recommendation

3.2 Federal, provincial and territorial governments, in collaboration with associations representing health care professionals and providers, should provide funding for:

(a) professional education and development opportunities for health care professionals and providers across the spectrum of health care to acquire the skills needed for optimal use of health information and communications systems; and

(b) developing, piloting and evaluating tools to support clinical decision making across the spectrum of health care.

Electronic decision support systems – a scenario for the near future

A family physician has been asked by a 54-year old woman to advise her whether she should take hormone replacement therapy (HRT). Many of her friends have been taking HRT since they became menopausal, but she is uncertain about the risks. Her physician takes a detailed history to assess her risks and tells his patient that he will review the most current research findings in medical information databases and then enter her information into a risk assessment program that will calculate the risks and benefits of her taking HRT for given periods of time. Between them, they will then be able to decide whether she should be on HRT and for what period of time. The physician is satisfied that he will be able to give this patient the best advice possible and that he will have increased his competence in this area to the benefit of his other patients. The patient will have the benefit of the latest information from well-conducted studies and know that the information has been converted to meet her individual needs.

As noted in the Council's interim report, it is important to recognize that living, breathing human networks underpin infostructures and communications networks. The introduction of these new infostructure applications will likely lead to integration of health care service delivery. It will also likely shift the balance of responsibilities among health care professionals and providers and among them, patients and the general public. A similar shift may occur among health institutions such as hospitals, community health institutions and long-term care facilities, as well as among them and the home.

These changes will be welcomed by some and resisted by others. Good will across institutional and professional boundaries will be vital to ensuring that these new systems contribute to strengthening health care services. While many of these issues will be successfully tackled by professional bodies and institutions, addressing some may require an ongoing process. In the Council's view, it would also be prudent to put in place a labour force strategy to address the effect of these changes on health care professionals, providers and workers, and to make sure that the necessary skills and knowledge are in place. Indeed, the Canadian Health Coalition called on the Council to "recommend that the federal government initiate a health labour force development strategy to ensure that training and skills needed to support a national health infostructure are available within the public sector."

Recommendation

3.3 Health Canada, in partnership with Human Resources Development Canada, other federal departments, provinces and territories, health worker organizations and health professional associations, should initiate a labour force strategy to:

(a) ensure the skills and knowledge base necessary to build, use and support the Canada Health **Info**way are available; and

(b) address labour policy, employment policy and occupational health and training issues.

Electronic Health Records

Patient-based health records are a fundamental cornerstone of provincial and territorial health infostructures. However, there is potential for serious violations of privacy. The Council believes that, with particular care, electronic health records can actually enhance privacy protection, improve patient care, enable telehealth, empower citizens through greater control of their own health records and serve as the foundation for an ever-improving information and evidence-based health system. Some of the Council's conclusions and recommendations on how the Canada Health **Info**way can ensure improved privacy protection appear here; others are set down in Chapters 2, 4 and 5.

The Need for Electronic Health Records

To understand the importance of an electronic health record, it is necessary to understand the present situation.

Obviously, no one should make a serious clinical decision without full knowledge about the patient. Right now, most medical records are handwritten by health care professionals. However, they are not always easy to read. Many first-time patients at physicians' offices and clinics arrive with no medical record – only their subjective impressions. The same holds true for those who return after a visit to a hospital, a procedure or other intervention. This absence of information may make diagnoses difficult and can cause physicians and health care professionals to order batteries of tests and x-rays which may be redundant, potentially unnecessary, expensive and even health threatening.

When people go to an emergency ward or a clinic outside their home town or province, it is often impossible for them to arrange access to their medical records by that local practitioner because these records are usually locked up in their own physicians' offices. Such barriers go against both the spirit and the letter of the principle of portability found in the *Canada Health Act*.

The difficulty of physicians and other health professionals and providers to get access to their patients' medical histories is due in part to the way the health care system is organized. As already noted, acute care, ambulatory care, mental health care, long-term care, physicians' offices and home care each form their own vertical silos and the horizontal communication among them is less than perfect. While a record of medical interventions and tests may exist in one silo, it is often difficult to fulfil a patient's request that this record be available in a timely fashion to a professional in another silo or that all his or her medical history be available to a particular practitioner.

Electronic health records – a scenario for the near future

> Stan visits a heart specialist for the first time following a referral from his family physician based on the results of some tests. Fortunately for Stan, the specialist had a cancellation and was able to see him in a few days. The heart specialist asks Stan several questions about the test results undertaken by his family physician. Stan is unable to provide all of the necessary technical information to the specialist. The specialist asks his permission to review his electronic health record so that they can see the exact test results. He agrees and the necessary information via the electronic patient record is provided for the specialist to provide an informed analysis of Stan's condition.

A provincial or territorial electronic health record of patients' past medical histories, electronically accessible to health care professionals and providers, but only on a "need-to-know" basis and under the strict control of patients, would eliminate most of these serious gaps in the information needed for patient care. Filling these gaps would lead to significant improvements in the quality, accessibility and efficiency of health care services. With an electronic health record, it would be easy for patients to ensure that physicians and other professionals and providers in every silo of the health care system had timely access to relevant portions of their medical records. Such electronic health records can pave the way to integrate and coordinate health care services delivery around patients and their needs.

Improved Privacy Protection

The Council is convinced that the electronic health record can be placed within a legislative, institutional and technological framework that will result in improved privacy protection within the health sector. The institution of fair information practices and measures to ensure compliance with them will be critical to this framework. As Manitoba's Ombudsman points out and the Council agrees, these should include: "(1) self-audit procedures for health care providers, institutions and agencies; (2) monitoring and oversight activities by external, independent bodies; and (3) criminal sanctions and civil law remedies for breaches of privacy."

"The historical focus on acute care led to the development of data collection and information retrieval mechanisms suited to the acute care setting. The application of information and communication technologies to all sectors in the health care continuum will benefit the public by reducing redundancy in information collection and storage and by facilitating continuity of care across care settings."

Ottawa-Carleton
Community Care Access Centre

When patients now confide in a physician or health care professional or provider, they trust that this information will be held in confidence. However, unless patients raise the issue there is sometimes uncertainty about what portion of this information will be passed on to other physicians and professionals and providers involved in a patient's care.

With an electronic health record, we believe that this situation will be improved. Physicians and health care professionals and providers should only receive personal health information on a "need-to-know" basis. In other words, they should be able to see only that portion of an electronic health record which they need to know so they can contribute to a patient's care. In addition, with an electronic health record, the principles governing informed consent will have to be spelled out much more clearly. In the Council's view, patients should be able to exercise control over what portion of their electronic health record is seen by other professionals and providers.

In addition, patients should have access to their own health records – a right under common law and in some provincial legislation. Such provisions should form part of all privacy protection legislation for the health sector. If people have access to their own personal health information, they will know what information about them has been collected, used and disclosed. They will also be able to verify that the information is accurate, complete and up-to-date. Fair information practices require any person who collects personal information to take reasonable steps to ensure the information is accurate, complete, up-to-date and appropriate for the purposes for which it is to be used or disclosed.

For electronic health records to be matched with a particular person to provide health care, each province and territory must have a system of personal identifiers. Without such identifiers, the record of one person could be confused with that of another, with potentially serious consequences for the health of both. Such identifiers already exist in most provinces and territories.

Some jurisdictions have proposed or put in place multipurpose identifiers to cover all of a person's dealings with government or, for example, transactions related to health and social services. The Council is strongly opposed to multipurpose identifiers and believes that they can lead to serious invasions of privacy. Such multipurpose identifiers make it too easy for government officials in one agency (e.g. the tax department or a publicly funded business development bank) to gain access to an individual's personal health records or combine records from several different areas to assemble a comprehensive profile. In our view, every Canadian jurisdiction should have legislative safeguards against the use of identifiers for multiple purposes.

Better Security

While technology is obviously not a cure-all and must be supplemented by privacy legislation and other measures, it can improve the level of protection of personal health information. A key element in the technological framework for electronic health records must be a capability to make full use of the modern technologies of encryption and authentication. Technologies to certify the identity of a person giving consent to the release of personal health information, as well as authenticating the validity of that consent, should be used by provincial and territorial health care systems at all levels. This same technology should be used to provide individuals with better control over their own health information. It should also be used to ensure that different health care providers receive only the portion of the health record relevant to their specialization and responsibility.

Health Canada is a full participant in the federal government's efforts to develop a public key infrastructure by early 1999. The new system lays out policies and processes for the secure transfer of health information. It will contain an encryption component to address privacy and access control, and allow digital signatures. Encryption involves the coding of information to ensure its security. In combination with an access key controlled by the patient, it can significantly enhance privacy protection by ensuring that only authorized persons can have access. Encryption is also used in telecommunications to ensure that only the person to whom a message is sent can read it.

Security systems can now potentially prevent access entirely to electronic information systems. They can also allow different people different levels of access to the same information at different times. The explicitness, versatility and automatic nature of such security systems have obvious applications in provincial and territorial health infostructures, where different health care providers may require different levels of access to the personal information. Such preciseness can be programmed into an electronic security system. The technology also allows a log to be created electronically of all people who access a given record. Printouts of the record and the eventual destinations of the printout in files or charts can be tracked. Patients can have access to this electronic log book of accesses to their records and what happens to printouts of that record.

However, health information systems can be complicated and costly. They also must function in an increasingly complex environment. System designers and stakeholders should therefore work together to anticipate potential problems and reactions before installing or modifying systems. All such projects should be subject to privacy impact assessments which take into account not only technical and legal dimensions, but also social, human and ethical issues.

> "The arguments for a move toward an electronic record are compelling. Such records are more likely to be legible, accurate, safe, secure and available when required, and they can be more readily and rapidly retrieved and communicated. They better integrate the latest information about a patient's care, for example from different 'departmental' clinical systems in a hospital. In addition, they can be more readily analysed for audit, research and quality assurance purposes."
>
> ***Information for Health:***
> ***An Information Strategy for***
> ***the Modern National Health Service***
> ***London, England, September 1998***

Although privacy enhancement, encryption and electronic security systems can improve protection of personal health information, they will not do their job if the people responsible for preserving the confidentiality of the information do not follow fair information practices. These in turn must be supported by responsible security procedures and practices, including the need to audit all accesses to personal health information. Institutions must develop internal practices and procedures, including self-audit procedures, for implementing privacy protection. The Council cannot overemphasize the need for all organizations with access to personal health information to implement such practices and procedures. As well, every Canadian jurisdiction should have in place an independent oversight body to evaluate compliance with fair information practices and legislative requirements.

Stringent security systems and practices should be in place at all levels of provincial and territorial health care systems and any other sites where health information actually linked or potentially linkable to individuals can be found. Access to this information should be audited. All such sites, whether their purpose is health care or research, should be subject to security audits. These audits should include periodic site inspections to ensure that the appropriate security arrangements and fair information practices have been fully implemented.

Degrees of Identifiability

In the Council's view, person-specific information in provincial and territorial health administrative systems should – in the context of effective privacy legislation and stringent security safeguards – provide a basis for creating the information resources for accountability and continuous feedback on factors affecting the health of Canadians. The benefits of creating such information resources, and the gaps they are intended to fill, are described in the next chapter. In most cases, data used to create these information resources are anonymized. However, it is important to understand that there are degrees of identifiability, depending on the process used to remove identifers.

According to a submission from the Information and Privacy Commissioner of Ontario commenting on the Council's interim report, "At one end of the spectrum, data are completely anonymous and not linked to any identifiers. This is the least sensitive type of health information. However, depending on how the anonymization process is carried out, there can be some degree of risk of re-identification of anonymized data through processes such as data matching or the reporting of results of analyses using small cells. Next on the spectrum, you have anonymous data linked to pseudo-identifiers, not to those corresponding to any real individual. From a privacy perspective, depending on how the pseudo-identities are created and implemented, this type of data may be viewed as being equivalent, in terms of its level of sensitivity, to completely anonymous data. Next on the spectrum, there is code-linked health information. This is information where the identifiers have been replaced with a code that, when necessary to do so, can be linked to information that would reveal the identities of the individuals. From a privacy perspective, depending on how the codes used to re-identify the data are created and controlled, this information is somewhat more sensitive than completely anonymous data or anonymous data linked to pseudo-identities. At the other end of the spectrum, there is completely identifiable health information. This is the most sensitive type of health information from a privacy perspective, with the greatest risks associated with it."

In the Council's view, it will not be enough to assume all identifiers of individuals have been erased before data are made available. A formal, transparent and explicit process should be put in place to review the degree to which a specific set of data can be defined as linkable to identifiable individuals. If such identification is possible, the more stringent requirements described below would have to be met before any research or other use of the data could be allowed.

Independent Ethical Review

In some cases, researchers may require data sets linked to personal identifiers or those with a higher level of potential identifiability. In these circumstances, the general rule should be that informed consent and stringent assurances about privacy protection and security arrangements are necessary before a researcher can have access to personally identifiable information.

Sometimes, such as when the nature of a research project is not known when data are being collected, it will be impractical to obtain consent from patients. At that time, the Council believes notice should be given about possible research use of the data in anonymous form. If this is not possible, notice should be given about possible research use of the data in personally identifiable form, following an independent ethical review. If the data can be linked to an identifiable person, we believe that the burden of proof should be on anyone proposing use of such information without consent to demonstrate that: (a) a tangible public good of significant benefit will result, (b) consent is impossible to secure at a reasonable cost, (c) less identifiable data will not serve the same purpose, and (d) no harm can occur to any person directly or indirectly as a result of this use of his or her personal information.

The Council believes that a transparent and explicit process should be put in place to weigh, on a case-by-case basis and according to recognized criteria, whether or not the public good resulting from a proposed research project is of sufficient importance and value to justify the proposed use of actually or potentially identifiable health information without consent. If justifiable and depending upon the degree to which the data can be linked to individuals, then the researchers should be placed under binding obligations. These obligations would ensure compliance with requirements for confidentiality, security and the destruction of actual or potential personal identifiers after a specific period of time. They would also ensure that no harm comes to any person as a result of this use of personal information.

The Council is aware that provinces and territories take different approaches to conducting such independent ethical reviews. In some provinces, commissioners responsible for privacy and access to information can play a role in such reviews. In other jurisdictions, ethical review panels at universities perform this function. Within a single jurisdiction, multiple approaches to ethical review may exist.

The Council has no desire to impose a single or federal solution on anyone and regards these different approaches as a strength in some ways. However, we do believe that there is a need for more transparency, greater coherence and more harmonization in the approaches taken to conducting such independent ethical reviews. It will be important to have a certain minimum level of consistency and integrity in the performance of such reviews. Also, it would be particularly helpful to harmonize the current multiple ethical reviews required for multiprovincial or pan-Canadian studies. To these ends, federal, provincial and territorial governments should work together closely on these matters and consider establishing an independent oversight mechanism to ensure that ethical review panels across the country operate consistently according to the principles in the report. As an alternative to, or as well as, establishing an independent oversight mechanism, governments could create in their respective jurisdictions ethical review panels that would operate according to those principles. All such mechanisms and panels should operate at arm's length from governments.

It is important to emphasize here that the Council opposes real-time electronic access for research purposes to personally identifiable information in provincial and territorial health administration systems. At times, it may be desirable to create pan-Canadian data sets. However, these would generally be made available only in relatively non-identifiable form, with consent or under the very narrowly defined circumstances already described. Indeed, the general rule for all research projects should be to provide, under the conditions described above, data with the minimum level of identifiability for the purpose in question.

Other Requirements

For health care purposes, the requirement will be very different. In emergencies, particularly when people are visiting another province or territory, people may want to allow a physician or health care professional or provider in that province or territory to have access to their records. For such access to be possible, it will be critical for provincial and territorial health information systems to have system architectures that make it possible to exchange information under these strictly controlled circumstances, with full privacy protection and security.

The Centre hospitalier ambulatoire de la région de Laval (Laval region ambulatory care hospital) is a demonstration site chosen by the Régie d'assurance médicale du Québec (RAMQ) for deployment of the health card system. The patient index and minimum clinical file of the regional program will be used as prototypes for an eventual Quebec system. This project will also enable use of the health card (both that of the citizen and that of the professional) in clinics and in the home. The project has two phases. The first, planned for fall 1998, involves delivery of the essential components – the health card system, the patient index and the minimum clinical file. The second, planned for summer 1999, will involve delivery of a case-monitoring system (individual care plan).

As the Council recommended in its interim report, provincial and territorial legislative frameworks should be harmonized to facilitate the privacy safeguards, security arrangements and information uses described above. Different jurisdictions now take different approaches to the protection of personal health information. We wish to emphasize that harmonization should not aim at some lowest common denominator with respect to privacy, but toward full, effective and enforceable privacy protection. Any jurisdiction falling behind in its legislative safeguards for privacy in the health area should not expect to benefit from exchanges of personal health information among jurisdictions, even for health care purposes.

Recommendation

3.4 Patient-based health records are a fundamental cornerstone of provincial and territorial health infostructures. However, they have the potential for serious violations of privacy. The Council believes that, with particular care, electronic health records can actually enhance privacy protection, improve patient care, empower citizens through greater control of their own health records and serve as the foundation for an ever-improving information and evidence-based health system. Consequently, the federal Minister of Health should work with his provincial and territorial counterparts to bring about developments relating to provincial and territorial health systems that will:

(a) improve patient care by creating provincial and territorial person-based, electronic health record systems. These will make accessible, on a need-to-know basis and under the control of patients, all relevant information about their past medical histories, including conditions and diagnoses, as well as treatments, medications and other forms of intervention (whether publicly or privately funded);

(b) provide legislative safeguards against the use of identifiers for multiple purposes;

(c) improve the security of health records by exploiting modern technologies such as encryption, authentication and electronic logging of all accesses made to a personal record;

(d) ensure a transparent and harmonized approach across the country, in light of the principles enunciated in the report, to the conduct of ethical reviews on a case-by-case basis of proposed health research projects which require access to individually identifiable records and which, for whatever reason, cannot be conducted on the basis of informed consent by patients. (Such ethical reviews should assess whether there is a sufficiently substantive public good expected as a result of a proposed project to warrant the project and the implied invasion of privacy.) To these ends, federal, provincial and territorial governments should consider:

(i) establishing an independent oversight mechanism to ensure that ethical review panels across the country operate in a manner consistent with the principles enunciated in this report; and/or

(ii) creating, if necessary in their respective jurisdictions, ethical review panels which would operate in accordance with those principles;

(e) ensure that the evolving provincial and territorial health information systems have a system architecture that makes it possible to exchange information under strictly controlled circumstances; and

(f) harmonize provincial and territorial privacy legislation to ensure that these objectives are facilitated.

Electronic health records have the potential to give patients access to their own health records. They may also provide far greater control over who has access to those records and how they may be used. However, the technology may be unfamiliar to many Canadians. Many others may not fully know how to exercise their rights to access their own information or to control who has access to that information and how it may be used. In the Council's view, health care professionals and providers, as well as federal, provincial and territorial ministries of health, will need to clarify these issues for the public.

Recommendation

3.5 Health care professionals and providers and federal, provincial and territorial health ministries should engage the public in discussions on the value and use of electronic health records.

Seizing the Telehealth Opportunity

Telehealth involves using information and communications technologies to deliver health information, services and expertise over short and long distances.[5] Its implications are far-reaching. It can make a fundamental contribution to improvements in the quality, accessibility and efficiency of health care services.

For example, telehealth can help link the many services in today's complex health system into an integrated whole. It can also ensure that services operate in a fully coordinated fashion. Such links are critical to ensuring that the varied programs and services in geographically separated sites of merged hospitals or the new institutes, community-based facilities and home care providers work efficiently together in the interest of patients.

Telehealth can also allow the health care system to deliver better quality services electronically to previously underserviced rural and remote areas and help local providers to deliver better care. Telehealth can enable remote areas to benefit from expertise and skill located in urban centres, resulting in significant improvements in the quality, cost-effectiveness and accessibility of health care services across Canada. Subsets of telehealth, such as tele-homecare, can take health care into the home, responding to the growing demand for community-based care as the population ages.

However, there are several barriers to deploying telehealth applications and integrating them into the health care system across the country.

Telehealth – a scenario for the near future

> Jenny, 10, hurt her neck in gym class and was taken to her local hospital in a rural community. Rather than transfer her by ambulance to a larger hospital a few hours away, her doctor used the telehealth network that connects all of the province's hospitals. The radiologist at the larger hospital examined Jenny's x-rays using video conferencing and medical devices that allow for Jenny's x-ray images to be transmitted between doctors and hospitals. Upon examining Jenny's x-ray, the radiologist at the larger hospital in discussions with the local doctor determined Jenny's injuries were not serious and she did not have to leave her community for follow-up.

For example, governments have invested in short-term pilot projects to support telehealth. However, according to the newly established Canadian Society for Telehealth, "The advancement of care delivery service innovations to operational levels across Canada... will require more than technology 'application' and an assortment of locally successful pilot projects. A strategy for successful transition must involve specific investments to address two important challenges. The first is sustainability, with the goal of integrating the successful projects into the regional health service frameworks as established and self-renewing. The second is generalizability, with the goal of transferring innovation and evaluation knowledge across jurisdictions and increasing the scale of services to a population level." To determine the specifics of such a strategy, the Society called for the establishment of a task force to create a pan-Canadian strategy for telehealth. The Council agrees fully on the need for federal, provincial and territorial governments to cooperate in creating such a task force.

[5] The definition is from Jocelyne Picot, *The Telehealth Industry in Canada: Part I – Overview and Prospects* (Industry Canada: November 1997).

Tele-homecare for elderly widower – a scenario for the near future

Despite a serious heart condition, widower Barry, 72, stays in his home and community. He does not need to move into a long-term care facility for several reasons. He has close friends and relatives nearby. He receives a variety of homecare services, including meal preparation and housekeeping. A nurse visits him several times a week to check his condition. And last but not least, on nights and weekends, a tele-homecare nurse practitioner is able to monitor his condition electronically and to phone him with reassurance or advice as needed. Should his condition suddenly present some danger, both Barry and the tele-homecare nurse are instantly alerted. In an actual emergency, the nearest ambulance service is also alerted.

Recommendation

3.6 Federal, provincial and territorial Ministers of Health should promote the development of a Canadian strategy for telehealth by establishing a telehealth task force. This task force should be composed of representatives of health care professionals and providers and the full array of health stakeholders, including the general public. The mandate of the telehealth task force should be to:

(a) develop a Canadian strategy for funding and the integration of telehealth into health care delivery;

(b) develop technical and professional standards; and

(c) address issues regarding licensure, liability and reimbursement of health care professionals and providers.

The Council does not believe that work on telehealth should halt while the task force is developing a Canadian strategy. Practical work to assess the needs of health care professionals, providers and institutions for telehealth applications, to undertake telehealth pilot and demonstration projects, and to support the training of health care professionals and providers can only add to the knowledge base of the task force. It will also strengthen the foundations for a national strategy. Organizations already active in the telehealth area, such as the Canadian Network for the Advancement of Research, Industry and Education, the Canadian Society for Telehealth and the Canadian Institute for Health Information, should also be encouraged to continue their work.

Work must also continue on illuminating the many ethical, legal and social issues surrounding telehealth, especially those related to shifts in responsibilities and expectations among professionals, institutions and the general public.

In the Council's view, this work should be central to the mission of Health Canada's Office of Health and the Information Highway.

Recommendation

3.7 To create a knowledge base for the telehealth task force and subject to evaluation by that task force, sufficient funding should be allocated to Health Canada to:

(a) develop, in partnership with provincial and territorial health ministries and associations of health care institutions and health professionals and providers, broadly accepted frameworks to assess the value of telehealth applications to physicians, health care professionals, providers and institutions, as well as the needs of these groups for such applications;

(b) undertake, in partnership with provincial and territorial health ministries and associations of health care professionals, providers and institutions, pilot and demonstration telehealth projects as a means of:

(i) evaluating within broadly accepted frameworks the costs and effectiveness of different applications and sets of applications, and

(ii) defining best practices;

(c) support national organizations (Canadian Society for Telehealth, Canadian Institute for Health Information, Canadian Network for the Advancement of Research, Industry and Education, and others) in their efforts to develop and implement the national telehealth strategy;

(d) support training for health care professionals and providers so that they can fully exploit the potential of telehealth; and

(e) support research, in conjunction with key stakeholders and the general public, on ethical, legal and social issues associated with telehealth.

Providing telehealth services across jurisdictional boundaries can raise complex issues because jurisdictions have different legislation, regulations and professional requirements governing delivery of health care. As well, when services are provided across jurisdictional boundaries, how will health care professionals and providers be reimbursed? If something goes wrong, who will be accountable?

For example, it may be necessary to allow the cross-jurisdictional licensing of professionals. The difficulty is that different jurisdictions have different rules. These rules generally make no regulatory provision for professionals or providers from other jurisdictions. These barriers can also exist between jurisdictions within a single province or territory, as well as among provinces and territories. However, several professional associations are examining these issues, and it is important that this effort be strengthened and that the telehealth task force work closely with them.

Recommendation

3.8 To build a sound foundation for a Canadian telehealth strategy and to address the basic issues of cross-jurisdictional licensure, reimbursement and liability, it is vital that:

(a) professional licensing authorities develop a mechanism of licensure that will allow interprovincial telehealth consultations;

(b) each provincial and territorial government develop, and coordinate through the Federal/Provincial/Territorial Advisory Committee on Health Services, a telehealth reimbursement policy that includes interprovincial payment agreements for negotiated services, recognizing that:

(i) telehealth services are a legitimate way to deliver health care,

(ii) practitioners providing these services should be compensated, and

(iii) reimbursement for services are currently limited to face-to-face encounters; and

(c) providers of liability protection, such as the Canadian Medical Protective Association and the Canadian Nurses Protective Society, develop appropriate liability protection products for medical practitioners providing telehealth services.

chapter four

Creating Information Resources

Information will be a basic foundation of the Canada Health **Info**way. Such information must be wisely and strategically used and made available in a way fully respecting individual privacy. It can also help improve the health of Canadians by ensuring that our health system continues to improve and becomes more accountable to Canadians. The benefits flowing from such strategic uses of information are far-reaching, as shown below. However, there are serious gaps and flaws in the information now available. These must be filled if the full benefits of the Canada Health **Info**way are to be realized. It will be critical to ensure that privacy protection is an integral part of our efforts to fill these gaps.

The Canadian Institute for Health Information (CIHI), Statistics Canada and Health Canada, on behalf of the Council, have created a *Health Information Roadmap* which takes a promising approach to filling these gaps. This action plan also addresses the key issue of accountability to the public through report cards on the health care system.

The Need for Strategic Information Resources

As stated in the Council's interim report, the Canada Health **Info**way should enable creation of strategic information resources. These resources should address everything from costs of health services and medical interventions to their impacts on health, or the influence of non-medical determinants of health. These new information resources should be the basis for a new accountability throughout the health sector. This information should also provide the basis for continuous improvement in the quality of health care by providing continuous feedback on the health impacts of medical interventions and health policies, programs and services. Such new information resources should be designed with a clear customer focus.

We have large gaps in our understanding of the factors affecting individuals' health over the medium to long term. For example, what is the longer-term effectiveness of sometimes competing procedures or interventions – such as coronary bypass surgery and balloon angioplasty? In the case of prostate cancer, what are the relative merits of drug therapy, surgery, or simply waiting and seeing? How do psychological interventions affect outcomes? What are the special health risks of different occupations? What are the long-term effects of many environmental hazards? To what degree, if at all, do people with low incomes or educational levels benefit from "equal access" provisions in the *Canada Health Act*? The Canada Health **Info**way should allow all stakeholders, and researchers in particular, to answer these questions and many others, then pass the answers on to health care professionals and providers in accessible and usable form. Such new data on health determinants and the outcomes of health care interventions has the potential, not just to improve health care in Canada, but to revolutionize it.

At present, no one in Canada can break down the costs of specific health interventions so that they are comparable across provinces and different kinds of health care providers. We also do not have a clear sense of the costs or effectiveness of services outside hospitals and doctors' offices – in clinics, long-term care facilities, laboratories and home care. The Canada Health **Info**way should allow all health stakeholders – and health managers in particular – without their having access to personally identifiable health information, to achieve a much more detailed and comprehensive picture of costs and thus improve management and cost-effectiveness within the health sector. More important, such information represents a key foundation for better coordination and even integration of services across the spectrum of care.

Health policymakers do not have sufficient access to evidence-based information on the costs and outcomes of different policies or their potential impacts on the health of large populations. The systems for collecting data that would allow a true evaluation of many health reforms – such as hospital restructuring or the closing of hospital beds – also do not exist. Data on community-based institutions and home care services which are to provide services in lieu of hospital beds remain scarce across Canada. The Canada Health **Info**way would enable the creation and analysis of information on the costs and health impacts of existing policies across the entire spectrum of care. It would also enable implications of other policy approaches to be projected. This continuing evidence-based feedback on policy will allow more effective decision making. It would also be available to the public as a basis for accountability.

Problems with Existing Information

In early 1998, CIHI, Statistics Canada and the Council joined forces to consult with more than 500 Canadians representing health care professionals, providers and users to identify evolving health information needs and priorities.

Throughout the consultation and from the results of recent opinion surveys, the Council found that Canadians are increasingly concerned about how well their health care system is meeting their needs. They worry about the ability of the system to continue to provide universal access to comprehensive care when and where it is needed.

The changes taking place in the health care system – regionalization, hospital restructuring, shifts toward community-based care – may be unsettling to those accustomed to how care used to be delivered. But is there good evidence to show that these reforms are a step in the right direction? Conflicting reports about the state of the health care system are common. Some claim the system is in crisis. Others insist that we still have one of the best in the world. Who is right, and who should be believed?

We want more information about how the health care system is functioning, and whether we are allocating our health care dollars in ways that produce the greatest health gains. Canadians want an accountable health system. Health care providers, managers and others who work within the system have also expressed the need for better information. They want to know if they are providing the best possible quality of care, if they are using resources appropriately, and if they are improving the health of the people they serve.

Canadians are also interested in knowing how to improve their health, and how to prevent disease. The health care system is a major contributor, but the public recognizes that there are many factors beyond the health care system influencing their health. The bottom line is that Canadians want to know about their health, and whether it is improving over time.

Canada's various health information systems now suffer from the following problems:

- **Data are fragmented** – Our data tend to be divided into silos – for example, one for hospitals, one for physician services, one for financial data. This is because we have tended to allocate budgets by creating separate funds for different providers. Many provinces have changed this approach and now use integrated delivery models that emphasize a seamless continuum of care and funding based on the population served. However, the organization of data has not kept up with the evolution of the newer health care delivery models. The result of this fragmentation is that we have trouble presenting a complete picture of the care that Canadians receive and how it compares over time or in different areas. Moreover, the data we do have on health status and on health determinants remain unconnected to data on health care services.

- **Data are incomplete** – We have good data on some services such as hospitalizations, but little data in other areas such as home care or preventive services. Our data on the resources used to provide services (e.g. health professionals, technology) and the cost of each service are patchy at best. As the Alberta Association of Registered Nurses emphasized in its comments on our interim report, "The absence of nursing components of health information means that for all our documentation on current patient and client health records, no permanent evidence of nursing's interventions and their effects on client outcomes currently exists on provincial or national health information databases." We have almost no data on the health impacts of present health policies or the services provided to patients. Data compiled by private health care providers also are not always captured for policy development and health program evaluation.

- **Data cannot be shared easily** – Our health systems do not always allow us to share or exchange data easily, even with completely anonymized or statistical data, let alone personal health information that has full privacy protection.

- **Data are not analysed to the fullest extent** – While extensive data exist on the various non-medical determinants of health, they are not always available in a standardized way. Also, these data are not being used to their full potential for analysing variations of trends in population health status. Data become useful to health care consumers and planners only when they are analysed. By analysis, we mean the identification of trends, variations and associations between different events. For example, we might want to know whether certain policies or programs were related to or resulted in improvements to health.

- **The results of research are not consistently reaching Canadians** – This failure is partly because there is no coordinated approach to providing information to Canadians about how to improve health and the health care system. As a result, information does not always reach its intended audience in a form that is accessible and easy to use. This issue is addressed in Chapters 2 and 3, as well as here.

The demand for health information is greater than ever. Technological advances have greatly reduced the costs of creating and maintaining a sophisticated health information system. The federal government and provinces have also embarked on major initiatives to improve the state of health information in their own jurisdictions (e.g. Alberta We//net).

What is now needed is a coordinated plan of action. No single government or organization can deal with the above problems alone. Cooperation at all levels – national, provincial, territorial, regional and local health organizations – is necessary for success.

Key Questions – Key Answers

Health information systems in the Canada Health **Info**way should provide information to answer two crucial questions:

- How healthy is the health care system?
- How healthy are Canadians?

The first covers the effectiveness, efficiency and responsiveness of the health care system. Generally, this type of health care system is one that offers the quality of care Canadians expect.

- Effectiveness considers whether or not we are doing things that improve the health of Canadians. Effectiveness is an essential component of what many providers and consumers describe as quality care. More simply, effectiveness asks the question: What works and what does not? The answer lies in our ability to measure what we are doing – whether it be health programs, policies or individual clinical decisions made by health care professionals and providers with their patients. Then, we must be able to measure the impact of our actions. What is the outcome of our interventions? Did we prevent a death, an illness, reduce disability, or improve quality of life?

"If we can identify groups in Canada with poor health, we can direct special attention to those groups most in need. If we know what works and what does not, we can save health care resources.... If we identify "best practices," we can share that information with other providers.... If we have information on responsiveness, we can encourage those who are managing the system to pay attention to the identified needs. And finally, if we have information on trends,...we can assess our overall progress."

- Efficiency explores whether we are getting value for money. Are we using the right amount of resources to achieve a desired result? Related to this question is the issue of cost-effectiveness. How do different interventions to treat the same condition compare with benefits and costs? Is one or the other more reasonable in this balance between benefits and costs? Is there a better place to spend the money?
- Responsiveness addresses how well the system is meeting the needs of the public, and is another aspect of quality of care. We may be doing things that work, and doing them efficiently, but the system may still not be meeting our needs. Are people satisfied with the care they receive? Do they have adequate access to services? How extensive are the waiting lists for necessary procedures? Are we maximizing our use of the most efficient and effective interventions?

The second question is broader, and addresses the basic objectives of the system: Is the health of Canadians improving? How does health status differ as a result of non-medical determinants of health, such as gender, ethnicity, socio-economic status and where Canadians live? How have improvements in health varied across groups? How do things outside the health care system, such as employment and working conditions, nutrition and housing affect our health? How important has the social environment, including community and family supports, been in sustaining our health? What about the physical environment and lifestyle risk factors?

We need to know how well our health care system is improving health. But we also need to know how modern medicine affects health, compared to other non-medical determinants of health. Addressing these non-medical determinants may lead us to further gains in health and reductions in health inequalities, which cannot be achieved by the health care system alone.

The ability to answer all of these questions allows the public, health service providers and planners to make better informed decisions. If we can identify groups in Canada with poor health, we can direct special attention to those groups most in need. If we know what works and what does not, we can save health care resources by eliminating ineffective interventions and expanding effective ones. If we identify "best practices," we can share that information with other providers and improve quality of care. If we have information on responsiveness, we can encourage those who are managing the system to pay attention to the identified needs. And finally, if we have information on trends and the distribution of health status among Canadians, we can assess our overall progress. This is a critical step for strengthening accountability within our Canadian health care system.

The report *Health Information Roadmap: Responding to Needs* is designed to provide the information needed to address all these issues.

Privacy Protection as a Design Feature

Privacy is a fundamental value in Canadian society. Individuals have important rights over when and how their personal information is used. Those who handle individuals' health data must maintain the highest standards of confidentiality. They have an obligation to keep secret the personal information entrusted to them. Our data systems must also be secure. There must be technical standards in place to ensure that unauthorized persons cannot access confidential data.

These values and principles must be at the forefront of any health information system development. They must be considered at each stage of the process – from database design and data collection to analysis and dissemination of results. Without this basic respect for the privacy of individuals' health data, the public will lose confidence in the health information system. One important means to achieve this objective is for members of the public to have transparent access to the privacy, confidentiality and security policies and procedures. They must also have information on how their health data are used.

Health information is used in different ways. The most important is in the treatment of a specific patient, where the person's identity is essential. The use we are concerned with here is statistical, in a search for patterns and trends. This latter analytical use generally requires person-based data but not people's names. However, it too raises concerns about privacy. These concerns have traditionally been seen as a tradeoff against data access for research and analysis in the public interest. A more positive way of viewing privacy is with the attitude that the best way for analysts to maintain the public's consent to use sensitive (but anonymous) health data is to show the public that privacy, confidentiality and security are being taken very seriously.

Chapters 3 and 5 address this issue. The *Health Information Roadmap: Responding to Needs*, the report containing the high-level action plan developed by CIHI, Statistics Canada and Health Canada, provides for privacy protection, confidentiality obligations and data security in each of its elements.

The *Health Information Roadmap* – An Action Plan for the 21st Century

The *Health Information Roadmap* foresees a strong health information system which is:

- secure and respects Canadians' privacy,
- consistent,
- relevant,
- integrative,
- flexible, and
- user-friendly and accessible.

Across the country, many initiatives are under way to address health information needs. Health care providers, regional health authorities, provincial and territorial governments, and many others are investing in improving health information. While these initiatives are important, they are not enough for building a pan-Canadian health information system. The action steps below describe what must be done to move from the data gaps described above to information solutions which will strengthen health care, improve the health of Canadians and enhance accountability throughout the Canadian health system:

- **Integrative, consistent data** – To move away from the present fragmented approach to data, it will be necessary – in the context of stringent privacy safeguards, confidentiality requirements and data security arrangements – to develop common standards for data and person-oriented (as opposed to incident-based) information in provincial and territorial health information systems.

- **Linking health determinants, interventions and outcomes** – The present provincial and territorial health records allow the study of health interventions, but these represent only some of the determinants of health status. Others include lifestyle, occupation, environmental factors, etc. Present data also do not permit assessing the effect of interventions on long-term health outcomes, particularly in a regional context. To remedy these shortcomings, it is proposed to greatly expand the scope and sample size of the National Population Health Survey.

- **Relevant, flexible data** – To end dependence on incomplete data, it will be necessary – in the context of stringent safeguards, confidentiality requirements and data security arrangements – to develop on an ongoing basis new or expanded data on health services and the costs of services, purge all deaths from provincial and territorial records, and integrate survey data on outcomes with survey data on interventions, health determinants and health status.

- **Sharing of data** – To eliminate unnecessary barriers to the sharing of data, it will be necessary – in the context of stringent privacy safeguards, confidentiality requirements and data security arrangements – to develop information exchange protocols that will allow the sharing of data under the appropriate conditions (as spelled out in the section on privacy).

- **User-friendly and accessible data** – To end situations where data are not analysed fully or the results of that analysis do not reach Canadians, it will be necessary – in the context of stringent privacy safeguards, confidentiality requirements and data security arrangements – to expand Canada's ability to analyse health data and disseminate the results by:

    - building up a Canadian capability for the analysis of health data to document better the health status of diverse populations within Canada and describe the determinants of health from a non-medical perspective;
    - developing measures of health system performance and report cards aimed at the public; and
    - disseminating the results of analysis in a form more accessible to users.

In the Council's view, *Health Information Roadmap: Responding to Needs* provides a plan for creating the strategic information resources called for in the Council's strategic framework. The roadmap proposes cooperation with interested provinces in building on their health records, suitably extended and integrated to track health interventions over time. It would supplement this information with cost data. It would develop and help to incorporate common data and technical standards. It would integrate information on deaths and, on a sample basis, information on health determinants and health status outcomes. Finally, it proposes expanding the analytic capacity needed to exploit these resources for the benefit of all. In summary, the roadmap would provide a flexible tool for productive studies of the health of Canadians and of their health system.

Recommendation

4.1 The report, *Health Information Roadmap: Responding to Needs*, developed by the Canadian Institute for Health Information, Statistics Canada and Health Canada, fully articulates a plan for the creation of information resources to support accountability and continuous feedback on factors affecting the health of Canadians. The federal Minister of Health should commit the necessary levels of funding (as detailed in the report) to ensure – in the context of stringent privacy safeguards, confidentiality requirements and data security arrangements – successful implementation of the plan.

The Council believes that the roadmap's plans for modernizing Canada's health information system must be implemented at a realistic pace. It will be necessary to establish collaborative partnerships and foster an environment for cooperation in these efforts. Balancing urgency and ambition with practicality, the roadmap suggests a phased strategy with both short- and medium-term deliverables, while taking into consideration the availability of financial resources and people's capabilities to carry out these projects.

It is important to note that the health information system as presented in the *Health Information Roadmap* will increasingly mirror the integrated health care system that is developing in Canada. The traditional "silo" thinking will be replaced with broader perspectives on the continuum of care. Fostering this change in perspective is essential to moving this system forward.

It is urgent that we move down these roads quickly. Canada's health care system has suffered from a lack of information for too long. Managing an enterprise that accounts for 10% of the economy and 30% of provincial and territorial budgets without good information is like flying a jumbo jet without an instrument panel.

Report Cards on the Health Care System

A key product of the analysis required to produce accessible and user-friendly data will be evaluations to tell Canadians how the system scores on the criteria of effectiveness, efficiency and responsiveness mentioned above. Such evaluations could provide a true basis for system accountability. Some provincial agencies have already published system-wide and sectoral performance profiles.

To carry forward this aspect of the roadmap, it will be necessary to work with provincial governments and partners across Canada to obtain a consensus on precisely what data are needed to provide a fair evaluation of the health system and ensure accountability. These endeavours will evolve over time, based on available data and the changing consensus on how to assess health system performance.

For example, the range of indicators that could be used in such report cards could include:

- **Health resources** – The focus here might be the size of health budgets, both in total and broken down by public and private sector, by federal and provincial or territorial government as well as by region or locality, and by health sector. Reports on the number of physicians, nurses and other providers per capita would be useful, particularly urban-rural comparisons. Surveys and other tools could also be used to determine the health care needs of communities.
- **Service delivery** – It might be useful to look at waiting lists and the degree to which patients were able to gain timely access to care within recommended waiting times in assessing service delivery. Another measure might be to look at, for example, reduction in unexplained variations between regions and institutions in selected interventions such as hysterectomies or ultrasounds. The degree of adherence to evidence-based clinical practice guidelines (e.g. those for immunization and breast cancer screening) could also be measured.
- **Outcomes** – A basic measure of outcomes is obviously avoidable readmissions to hospital or the avoidance of adverse events related, for example, to pharmaceuticals or the blood system. Reductions in mortality due to medically treatable diseases could also be measured. Another important indicator could be improvements in health status (ranging from reduction in chronic illness, to effective management of mental health disorders, to recovery of daily functioning ability after acute care episodes). It might also be useful to look at degrees of improvement in pain management and coping with chronic conditions.
- **System management** – Report cards on the management of the health care system could focus on the degree to which resources were realigned relative to health care needs within the population; patient-centred information systems were used; the delivery of services was integrated and focussed on patient needs; communication took place among health care professionals and providers; and management tools for planning and measuring utilization of services were used across the spectrum of care.
- **Patient satisfaction** – Patient satisfaction could be measured with survey and other tools to determine how easy it was to get access to services, how responsive those services were to individual needs and preferences, and how competent and appropriate the service provider's intervention was.

An important part of these measures could be to identify exemplary practices, which could yield practical information on how to improve care. As Canada becomes more sophisticated in using and analysing person-oriented information in the context of stringent privacy safeguards, confidentiality requirements and data security arrangements, it will be possible to move toward measuring the effectiveness of specific interventions and the efficiency of different interventions.

Recommendation

4.2 As a key element of the *Health Information Roadmap*, the federal Minister of Health should, in partnership with his federal, provincial and territorial counterparts and health stakeholders across Canada, support evaluative analyses and consensus building to develop yardsticks and fair measures of health care system performance and the health status of Canadians. These analyses would form a basis for report cards to the public that will improve the overall accountability of the health care system.

It is likely that a significant number of outbreaks of communicable diseases, notably food-borne illness, go undetected in Canada each year. Improved health surveillance – the tracking and forecasting of a health event or determinant, the interpretation of data and the rapid sharing of information – could reduce the number of individuals affected by outbreaks. For example, an outbreak of food poisoning by a particular food product last year affected 800 people across Canada. With the development of faster communication and information networks, it is estimated that more than 80% of these cases could have been prevented.

Health Protection Branch, Health Canada

Need for a National Health Surveillance Network

Three Health Canada initiatives form key parts of the action plan: the Canadian Health Network, the First Nations Health Information System and the National Health Surveillance Network. The first two are discussed in Chapters 2 and 7, respectively, but the National Health Surveillance Network deserves particular attention.

Surveillance of health, demographic and social indicators is essential to our ability to manage and improve the health system and the health of the population. Health surveillance supports public health and population health activities by systematically identifying emerging issues and monitoring the effectiveness of intervention strategies. In addition, health surveillance activities provide timely and relevant information on diseases and other health risks as well as outcomes to support planning, policy development and program changes.

At present, the creation of data for public health surveillance usually occurs locally, in hospitals or other institutions, in general or targeted populations, and in individual provinces and territories. Aggregation and further analysis are done at the federal level by the federal government. However, there is no planned, coordinated, pan-Canadian health surveillance network that enables the timely, accurate exchange of information and knowledge which can then be distributed across the country for action by the public health community.

Last year, Health Canada began developing a health surveillance infostructure, which will eventually become the federal portion of a collaborative network of people and organizations, each providing standard health surveillance data (e.g. on incidents of disease, laboratory test results) electronically as health events are recorded. This National Health Surveillance Network will allow the timely monitoring of the health of a region, a province, a territory, the nation as a whole or the world through exchanges of information with other countries. The network will also provide decision support applications to help analyse data. Critical to the success of this initiative will be the strong support of federal, provincial and territorial health ministers.

Recommendation

4.3 Federal, provincial and territorial Ministers of Health should collaborate in supporting the development of a National Health Surveillance Network that will allow the timely monitoring of the health of a region, a province, a territory or the nation as a whole in a global context.

chapter five

Improving Privacy Protection

The Canadian Medical Association (CMA), in its comments on our interim report, stated, "We believe that the development of a robust health infostructure is essential to better health system planning and research and ultimately better patient care. However, in developing this structure it is important to ensure that the privacy of patients and the physician's duty of confidentiality is adequately safeguarded." The Council agrees completely. It is also convinced that the Canada Health **Info**way can and must lead to improved privacy protection within Canada's health sector.

To this end, the Council considers privacy protection one of the four strategic goals for, and a key design feature of, the Canada Health **Info**way. The three previous chapters, which focus on the realization of other strategic goals, also contain a discussion of privacy. Chapter 3 in particular contains an extensive recommendation on how to ensure the privacy of electronic health records. To fully appreciate the Council's position of personal privacy protection, it is necessary to read Chapters 2 to 4.

This chapter focuses on the key mechanisms that should be in federal, provincial and territorial privacy protection legislation relating to health information. As an introduction to this discussion, we shall draw heavily on our interim report to lay out some key privacy concepts and considerations.

We wish to thank Canada's federal, provincial and territorial privacy commissioners for their comments and helpful feedback on our interim report. Their recommendations have helped us make privacy protection an even more pivotal concern in our broad strategy to develop and implement the Canada Health **Info**way.

In considering the Council's approach to privacy in this report, it is important to consider what it is not. We have not spelled out specific legislative provisions or offered instructions for drafting privacy legislation. Nor do we lay out all of the rules and procedures that should govern the protection of personal health information, confidentiality obligations and effective security arrangements. Privacy is a very complex issue, and such detail is beyond the scope of this report. As with the other basic strategic goals for the Canada Health **Info**way, our mandate is to present broad strategic directions, general principles and approaches that would improve privacy protection within Canada's health sector. It will be the responsibility of those who come after – including Canada's privacy community – to bring about sound privacy protection.

Privacy Concepts

As noted in our interim report, Canadians in survey after survey have expressed concern about loss of privacy in the new electronic environment and, more specifically, their control over personal information. Few such categories are more sensitive than personal health information. In its own consultations, the Council also found much anxiety about this issue among stakeholders in the health sector and representatives of the general public.

Privacy is often defined as the right to be free from intrusion or interruption. It is linked with other fundamental human rights such as freedom and personal autonomy. In relation to information, privacy involves the right of individuals to determine when, how and to what extent they share information about themselves with others.

Privacy can also be a concern for groups such as Aboriginal and immigrant communities. These communities worry that research on their members could be released to the media without notice and used in a negative way. This emerging issue is growing in importance and, in the Council's view, should be a serious consideration in the context of ethical reviews of proposed research projects.

Safeguarding privacy for individuals includes protecting information about oneself – that is, any information that can be linked to a person who can be identified. Protection of personal information requires adherence to fair information practices in managing such information.

Confidentiality refers to the obligations on one person to preserve the secrecy of another's personal information. Security refers to the procedures and systems used to restrict access and maintain the integrity of that information.

As noted in our interim report, privacy, although a fundamental value and right, is not an absolute right in law and in Canadian society. For example, in criminal cases or in matters affecting public health, there are justifiable circumstances in which privacy must be weighed against the public good. Such balancing should never involve considering the sacrifice of personal privacy on a broad scale, even to achieve some overwhelming public benefit. Rather, the consideration might relate to a case-by-case review to assess whether a presumed public benefit is of sufficient value to warrant – in that case and for that purpose – a limited intrusion of privacy with specific restrictions and safeguards.

Key Legislative Mechanisms

Significant variations now exist in provincial and territorial laws, regulations and guidelines for privacy and the protection of personal health information in the public sector. Quebec has legislation which also applies to the private sector. The federal government also brought forward in October 1998 legislation (Bill C-54, the *Personal Information and Electronic Documents Act*) that would apply to those parts of the private sector under federal jurisdiction for the next three years. Three provinces have introduced or passed new legislation intended to protect personal health information. However, compatible approaches are not always taken.

In the Council's view, as noted in its interim report, a real danger exists that Canada could end up with many different approaches to privacy and the protection of personal health information. Different approaches could make it difficult, if not impossible, to improve the portability of services or create information resources needed for accountability and continuous feedback on factors affecting the health of Canadians. In some cases, any exchange of information might be prohibited by law in those jurisdictions that do not provide adequate protection for personal health information. Refusal to share information in such circumstances would be entirely defensible. However, it is to be hoped that the circumstances justifying such a refusal can be avoided in Canada.

For these reasons, in its interim report the Council called on the federal Minister of Health to take the lead in encouraging an accord among provincial, territorial and federal governments to harmonize the approaches in their respective jurisdictions to privacy and the protection of personal health information taking into account best practices internationally. The Council also recommended that all governments in Canada should ensure that they have legislation to address privacy protection specifically aimed at protecting personal health information through explicit and transparent mechanisms.

Several key principles, approaches and mechanisms should be incorporated in such legislation. In depicting them, however, we are aware that our list is not comprehensive, all-inclusive or definitive, either here or within ***Recommendation 3.4***. In responding to our interim report, the CMA drew attention to its recent officially announced privacy code which addresses the seriousness of the association's commitment to privacy. The code represents an important contribution to the deliberations of Canadians and legislators on how to safeguard privacy across the health domain. In keeping with our mandate, we have set out broad legislative directions relevant to the electronic health infostructure without specifically endorsing a particular set of proposed codes.

It is critical that privacy protection legislation define health information in broad terms to include information collected by both the public and private sectors. Obligations to protect health information should apply equally to both.

Such legislation should contain a clear definition of personal health information and address the differences in the degree to which data can be made personally identifiable, as described in Chapter 3.

Within the legislation, there should be a transparent definition for custodians or trustees of personal health information – the persons responsible for ensuring the protection, confidentiality and security of personal health information. Their obligations should be precisely defined. They should apply equally to public and private sector organizations, as well as to organizations acting as an agent or contractor for the custodian. The definitions of guardians (e.g. for minors) and their obligations should also be clearly set down in the legislation.

The legislation should also contain a precise definition of free and informed consent, as well as a statement of principle that informed consent should be the basis for sharing personal health information.

"Exemptions" to this requirement for informed consent should also be clearly set out in law. More specifically, legislative guidance should be provided on how to balance the right of privacy with the public good for research purposes to implement the coherent and harmonized pan-Canadian system for independent, ethical review recommended in Chapter 3. The legislation should also contain a clear prohibition against all secondary commercial use of personal health information.[6]

Provisions regulating secondary uses of non-identifiable health information must form part of the legislation. Such provisions should address privacy concerns surrounding the degree to which such data might be linked back to an identifiable individual, as described in Chapter 3.

To prevent such potential abuses, the legislation should set clear limits on access to and use of health information by third parties outside the health care system. To prevent the serious invasions of privacy that can result from the unrestricted linking of personal health information with other kinds of information on the same individual, the legislation should contain provisions prohibiting the use for any another purpose of unique personal identifiers in health information systems.

6 The need for rigorous definition of free and informed consent and a ban on all secondary commercial use of personal health information is apparent from the following example provided by Ann Cavoukian and Don Tapscott in their 1995 book, *Who Knows: Safeguarding Your Privacy in a Networked World*: "...it may be the case that you, through little choice of your own, have given (personal health) information to (direct marketers). You may have been forced to consent to the release of your information for a wide variety of purposes. We say 'forced' because when faced with dire consequences, such as being denied medical insurance, you have little real choice other than to consent to what is being asked of you. This type of consent is neither free nor informed, but is frequently obtained by having individuals sign broad release forms that permit wide-ranging secondary disclosures to third parties."

Finally, such legislation should include measures to remedy breaches of privacy, including criminal sanctions and civil law remedies.

Recommendation

5.1 In harmonizing and strengthening the protection of personal health information across jurisdictions, governments should ensure that their privacy legislation for health embodies the following mechanisms and principles:

(a) a clear definition of health information, broad enough to incorporate health information collected in public and private systems and to ensure that equal obligations and penalties apply to both public and private sectors;

(b) a definition of personal health information, which takes into account the spectrum of potential identifiability in the case of health information;

(c) a definition of a custodian or trustee of personal health information, and a custodian or trustee's obligations, including provisions for ensuring that these obligations apply equally to private sector organizations and organizations acting as an agent or contractor for the custodian;

(d) definitions of a guardian (e.g. for a minor child or a mentally incompetent person) and of a guardian's obligations;

(e) a definition of what constitutes informed consent, as well as a clear statement of principle to the effect that informed consent should be the basis for sharing information;

(f) a precise definition of "exemptions" to this requirement for informed consent – specifically provisions that give clear guidance on how to balance the right of privacy with the public good for research purposes;

(g) provisions prohibiting all secondary commercial use of personal health information;

(h) provisions setting clear limits on access and use of health information by third parties outside the health care system;

(i) provisions regulating secondary uses of non-identifiable health information, taking into account the spectrum of potential identifiability of such information;

(j) provisions prohibiting the use of personal health identifiers for other purposes, to prevent the potential serious invasions of privacy attendant upon potential access to personal health information beyond the health domain or the combination of records from several different areas to assemble a comprehensive profile; and

(k) provision for remedies in the case of breaches of privacy.

chapter six

Standards

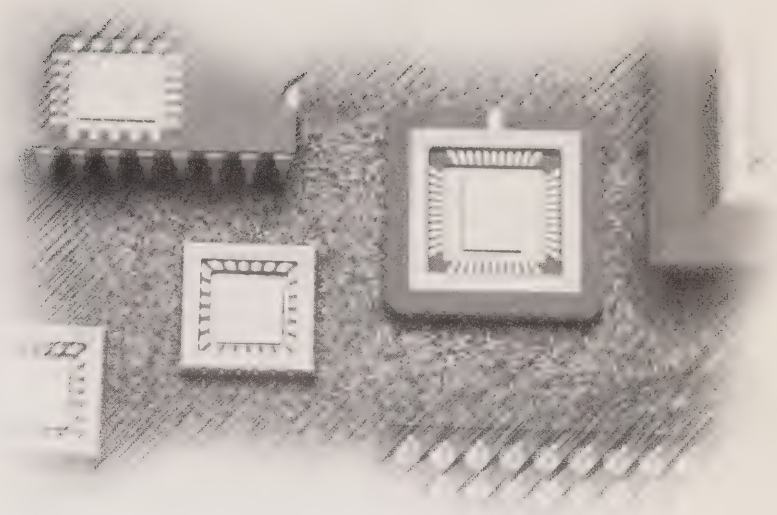
As noted in Chapter 1, the Canada Health **Info**way will not be a single massive structure. It will be composed of provincial and territorial as well as federal health infostructures and those of regional health authorities within provinces. These are already being designed or implemented across Canada. Each of these will retain its identity and integrity.

The Canada Health **Info**way will involve the potential for two kinds of information transfers among provincial and territorial health infostructures.

- First, the Health **Info**way should allow for the possibility of interprovincial transfer of a patient's health record for the purpose of treating that patient and subject to his or her control.
- Second, the Health **Info**way should allow the precisely controlled pooling of information from provincial and territorial health records for research purposes, under the conditions in Recommendation 3.4 and legislative provisions in Recommendation 5.1.

It will be necessary to achieve a significant level of harmonization among the standards used in provincial and territorial health information systems to ensure the possibility for such controlled interconnections.

This chapter will look briefly at the concepts of standards and privacy and the relationship between them. It then moves on to a discussion of the means available to achieve compatible standards in a Canadian and world context. Finally, we will examine the need to test for compatibility among applications used in health information systems.



Standards and Privacy

Standards are documented agreements containing technical specifications or other criteria to be used consistently as rules, guidelines or definitions to ensure that materials, products, processes and services are suitable for their purpose. Some standards created to meet safety requirements are enforced by law. Others establish rules affecting how people behave and technology operates.

The number of different kinds of standards is enormous. In the Canada Health **Info**way, they might include technical standards for hardware and software, data standards to ensure the quality and comparability of data, information exchange protocols to allow the exchange of information, and clinical standards to ensure, for example, that a piece of equipment or system is appropriate for a given clinical purpose.

The compatibility of standards within and across provincial and territorial boundaries will be critical to many of the functions performed by the Canada Health **Info**way. One major reason for striving for compatibility in standards is to ensure that whenever information crosses provincial and territorial boundaries – whether for treatment or research purposes – the same terms mean the same thing and such transfer of information is technically possible. As Chapters 2, 3 and 4 show, it is vital for individuals,

communities, physicians, health care professionals and providers, institutions and jurisdictions to be able to communicate with each other and exchange information across provincial and territorial boundaries. This exchange, of course, would be subject – to the degree personal information is involved – to the stringent privacy safeguards, including confidentiality requirements and security arrangements, outlined in those chapters. It is the Council's view that effective privacy protection should be a prerequisite for the use of personal health information – within or across provincial and territorial boundaries.

Developing and Implementing Compatible Standards

As the Council pointed out in its interim report, standards emerge in many ways. Sometimes, governments make standards mandatory when the public interest is at stake – for example, when health or safety or personal privacy is at issue. Market forces can create a de facto standard when some product – such as Microsoft Windows™ – achieves dominance.

Other standards arise through consensus building by standards development organizations or other kinds of associations. The process can be slow, labour intensive and time consuming.

"...governments, professional associations, hospitals and community health organizations have been building various health information systems...under the umbrella of provincial and territorial governments. Until recently, ensuring that these systems are...compatible has not received much attention."

In Canada, the largest such organization is the Canadian Standards Association (CSA). The CSA addresses a wide range of industrial sectors – including information and communications technology – and has sophisticated mechanisms for consensus building.

In 1996, the Canadian Institute for Health Information (CIHI) established a Partnership for Health Informatics/Telematics to define and adopt emerging standards. Its purpose is to ensure the development of a set of health information standards for Canada that are not redundant or in conflict with other standards. The partnership has more than 300 members from associations, professional and provider organizations, systems vendors and government ministries which directly participate in and fund the standards development process. Talks have already started between CIHI and the CSA to explore the possibility of a standards development organization for health information and telematics, based on a partnership between the two organizations.

The importance of standards in health information and telematics has been acknowledged repeatedly at the international level. The International Standards Organization (ISO) established in 1998 a technical committee to look at standards in this area. Many developed countries, including the United States, have created formal standards development organizations that focus specifically on health informatics and telematics with a mandate to participate in ISO deliberations. The Standards Council of Canada (SCC), under the umbrella of Industry Canada, is the body that creates standards development organizations in Canada. The SCC asked CIHI to take a lead role for Canada in a meeting of the ISO technical committee this year.

In Canada, governments, professional associations, hospitals and community health organizations have been building various health information systems within their respective jurisdictions. Most of this work is being carried out under the umbrella of provincial and territorial governments. Until recently, ensuring that these systems are at least minimally compatible has not received much attention. It would also be desirable to achieve greater participation by citizens in this process.

Despite much progress, Canada has a long way to go in developing compatible standards. In its interim report, the Council recommended that Canada should develop a strong, Canadian capability for cooperatively managing the development and adoption of compatible standards in the areas of health information and telematics. It also recommended developing strong links to international standards deliberations. In the Council's view, such a strong Canadian capability can be achieved only if CIHI receives sufficient funding for standards development from federal, provincial and territorial governments. Its partnership initiative should be expanded to allow more participation by citizens in the standards development process. Because health care is largely publicly funded and administered, it is also critical that CIHI have a formal process for identifying, ratifying and implementing standards in conjunction with federal, provincial and territorial Deputy Ministers of Health to ensure official support from their ministries and governments. CIHI should also continue to play a lead role in Canada in international standards deliberations in the area of health informatics and telematics. Finally, Industry Canada and the SCC should establish a standards development organization for health informatics and telematics based on a partnership between CIHI and CSA, to draw on the strengths of both organizations.

Recommendation

6.1 To strengthen significantly the development and implementation of standards in health informatics and telematics, it is necessary that:

(a) federal, provincial and territorial governments provide sufficient funding for standards development in health informatics and telematics to the Canadian Institute for Health Information (CIHI);

(b) measures be taken to ensure citizen participation in the standards development process through, for example, the CIHI partnership initiative;

(c) CIHI achieve a formal process for identifying, ratifying and implementing standards with federal, provincial and territorial Deputy Ministers of Health to ensure buy-in from provinces and territories at the level of officials;

(d) CIHI play a lead role for Canada with respect to international standards deliberations in the area of health informatics and telematics (e.g. ISO TC 215); and

(e) Industry Canada and the standards Council of Canada establish a standards development organization for health informatics and telematics, based on a partnership between CIHI and the Canadian Standards Association.

Testing for Compatibility

The all too frequent difficulties associated with hardware and software conflicts on a desktop computer will be nothing compared to the challenges posed by the complex networks forming the Canada Health **Info**way. Within the infostructure, there will be many layers of networks – first at the institutional and local or regional levels and then moving on to the provincial, territorial and federal levels and ultimately to the interjurisdictional level. Each component network will have its own hardware, software and applications – including electronic security systems and privacy-enhancing technologies to protect personal health information – purchased from different vendors at different times. All of these will be expected to work together in the Canada Health **Info**way.

*"The all too frequent difficulties associated with hardware and software conflicts on a desktop computer will be nothing compared to the challenges posed by the complex networks forming the Canada Health **Info**way."*

The process of developing and implementing standards through CIHI and the CSA, as described above, will be important in meeting this challenge. Market forces will also generally serve to pressure vendors into trying to ensure that their products are compatible with others. However, the electronic environment of a health infostructure is so complex and many of its functions are so critical to the health and lives of patients that it will not be sufficient to accept vendors' assurances about compatibility. Nor can it be assumed that a standards development and implementation process will reveal all potential sources of conflict. For these reasons, the Council believes it is only prudent for Health Canada to work with the Canadian Network for the Advancement of Research, Industry and Education and other organizations to ensure that facilities are available to test the compatibility between new and existing products before they would actually be used on the networks forming the Canada Health **Info**way.

Recommendation

6.2 Health Canada should work with the Canadian Network for the Advancement of Research, Industry and Education, and others as appropriate, to ensure that test-bed facilities are available to analyse the compatibility of new health application products with other health applications, including those already being used on Canadian health networks.

Because many compatibility issues can be resolved only through actual experimentation, the Council also believes that Health Canada should offer incentives for provincial and territorial governments to work jointly on projects to refine and resolve such issues.

Recommendation

6.3 Health Canada should provide incentives for provincial and territorial governments to develop and carry out joint projects that will refine and resolve compatibility issues in health networks across Canada.

chapter seven

An Aboriginal Health Infostructure

Health Canada has a special responsibility for the delivery of health care services to First Nations and Inuit communities. The Advisory Council commissioned two papers by the Assembly of First Nations (AFN) to explore Aboriginal health information needs and the potential of an Aboriginal Health Infostructure.[7] This chapter is based largely on these papers. They show that, if an Aboriginal Health Infostructure is to emerge, it must reflect the aspirations of Aboriginal communities. They must also be fully consulted throughout its development and implementation. Secondly, the unique needs of Aboriginal communities demand an approach to building a health infostructure that is appropriate to those needs.

In the Council's view, the recommendations below represent a strong foundation for advancing the health infostructure in Aboriginal communities and should be used in consultations with representatives of all Aboriginal communities.

A Unique Approach to Health Information

There are important differences between Aboriginal and other Canadian communities. These must be taken into account when developing the Canada Health **Info**way.

For example, First Nations and Inuit communities have a recognized fiduciary relationship with the federal government. Particularly in the case of Metis and urban Aboriginal communities, jurisdictional disputes between levels of government complicate this relationship. As well, all Aboriginal groups insist on "a historical and legal right to self-government," which means the right to develop autonomous institutions mandated to serve the needs of each population. For First Nations, these rights are grounded in Treaty agreements. For other Aboriginal groups, these rights flow from various legislative agreements.

The Aboriginal population in Canada is also quite varied, belonging to several distinct cultural and political communities with unique concerns and needs. Most health information now available on Aboriginal peoples pertains to the Inuit, and to First Nations people living on reserve. Very little is available to describe Metis and urban Aboriginal people. Aboriginal populations also make up widely varying proportions of the general population in different geographic regions. In some instances, they make up the majority.

[7] Assembly of First Nations, *An Aboriginal Health Infostructure – Critical Issues and Initiatives* – Background Paper, AFN, October 1998, Ottawa; Assembly of First Nations, *An Aboriginal Health Infostructure – Social/Political/Operational Issues* – Background Paper, AFN, October 1998, Ottawa.

Poverty, lack of economic opportunities and low educational attainment severely afflict the Aboriginal population. All have been recognized as contributors to poor health status, and the health status of Aboriginal people is much worse than that of the average Canadian. Health care services have eased this situation somewhat. However, they have also contributed to a gradual erosion of traditional, holistic approaches to health and healing.

Research on Aboriginal health problems and their interpretation by external agencies such as universities, government departments and the media have caused growing concern during the past few decades. For this reason, any attempt to develop health information systems without the full participation of Aboriginal communities will fail.

Aboriginal communities across the country are developing new institutions and ways to foster community development and wellness for their people. Those federal, provincial and territorial programs allowing for autonomous and creative Aboriginal approaches to economic and community development have been the most successful in supporting Aboriginal efforts to improve social and health conditions in their communities.

'Aboriginal communities across the country are developing new institutions and ways to foster community development and wellness for their people. Those federal, provincial and territorial programs allowing for autonomous and creative Aboriginal approaches to economic and community development have been the most successful in supporting Aboriginal efforts to improve social and health conditions in their communities."

Given this situation, certain principles should govern our approach to ensuring that the Canada Health **Info**way meets the needs of Aboriginal communities.

- **Self-determination** – Experience shows that successful developmental initiatives occur in an emerging context of self-determination. In many communities, particularly those of Inuit and on-reserve First Nations, this context is best characterized as a move toward self-government. The AFN believes that "Aboriginal people are not an 'interest group' in the same sense as other constituencies consulted by the Advisory Council on Health Infostructure. For historical and judicial reasons, Aboriginal people have fundamental rights to autonomous institutional development that cannot be met without a commitment to independent institutional development."
- **Knowledge is power** – A necessary precondition for self-government is the institutional capacity to direct and control how the information used to determine policy, and implement and evaluate programs is assembled. As the AFN points out, "Control over databases, research and the analytical process of linking health information to policy and program outcomes is essential for Aboriginal communities."
- **Inequities in human resource capacity and institutional development** – Aboriginal communities are now making large strides in creating new educational resources and structures. Such capacity building in developing and managing information is urgently needed if a health infostructure is to be useful or meaningful to Aboriginal communities. According to the AFN, "the obvious analogy of the health infostructure to the development of the national railroad can be extended to Aboriginal people. Without the institutional and human resource capacity to participate as equals in the development of the health infostructure, the effect on Aboriginal communities could be as destructive as the historical impact of the railroad."

In light of these realities and in recognition of these principles, it is the Council's view that there should be an Aboriginal Health Infostructure, strategically interconnected to the Canada Health **Info**way. However, it should be an autonomous and distinct institutional development consistent with Aboriginal interests.

Recommendation

7.1 Health Canada should consider an Aboriginal Health Infostructure, strategically interconnected to the Canada Health **Info**way, as an autonomous and distinct institutional development consistent with Aboriginal interests.

Given the strong tradition of autonomy in Aboriginal communities, and their extensive variety with respect to situation and needs, it would be unwise to assume that top-down plans can be developed for an Aboriginal Health Infostructure. Aboriginal groups will have to conduct extensive consultations with Aboriginal communities on the principle of an Aboriginal Health Infostructure, on how best to develop and implement it, and/or on Aboriginal participation in the Canada Health **Info**way. Because Aboriginal communities are scattered across the country, many in remote, isolated locations, resources will be needed for such consultations.

Recommendation

7.2 Health Canada should provide financial resources for Aboriginal groups to undertake further consultation and communications with governments, private sector groups and each other to confirm and further develop the concept of the Aboriginal Health Infostructure and define plans for its development and implementation and/or determine the nature and scope of Aboriginal participation in the Canada Health **Info**way.

Steps Toward an Aboriginal Health Infostructure

For an Aboriginal Health Infostructure to succeed, several key steps must be taken. First, it will be vital to ensure that people in Aboriginal communities – particularly health professionals and providers, but also community workers – can take advantage of a health infostructure. Second, a serious need exists to build on present initiatives intended to develop comprehensive health information on Aboriginal people. Third, the communications infrastructure serving many Aboriginal communities requires considerable attention if such health information is to be available at the right time.

The Human Basis for a Health Infostructure

According to the AFN, a dedicated effort will be required to ensure that Aboriginal communities have the capacity in human terms to take full advantage of an Aboriginal Health Infostructure. What is needed is training in information technology and the development of sophisticated management skills.

At present, many Aboriginal health care workers lack the training to use computers, modems and the Internet effectively. In many cases, training dollars and programs have simply been unavailable to these community health workers, who are often the mainstays of their local health care systems. They often also lack the time to take advantage of the new technologies. As the AFN comments, "It is the Aboriginal take on catch-22. Aboriginal health care workers do not have the training resources or the time, in the face of heavy workloads, to access the training that will enable more efficient use of time in the workplace. Their unfamiliarity with and fear of new information technology is an effective barrier that impedes them from attaining basic computer skills that would enhance understanding and comfort levels with this technology."

"[Aboriginal health care workers'] unfamiliarity with and fear of new information technology is an effective barrier that impedes them from attaining basic computer skills that would enhance understanding and comfort levels with this technology."

Assembly of First Nations
November 1998

There is also a need to develop new managerial capabilities in Aboriginal communities as a basis for fully taking advantage of the opportunity posed by a health infostructure. As the AFN puts it, it is a matter of "developing and applying abilities to govern and manage, solve problems, respond to new situations, make informed, evidence-based decisions, to strategically plan, to identify and set priorities, to evaluate, to effectively and efficiently manage resources (human and fiscal) and to take responsibility for the success or failure of health interventions and have the commitment to try again."

It will be particularly important to ensure that resources for training aimed at developing such capacities are made available to meet needs directly relevant to an Aboriginal Health Infostructure and Aboriginal participation in the Canada Health **Info**way.

Recommendation

7.3 Health Canada should ensure that resources committed and dedicated for capacity development and training are designated for Aboriginal people to support the Aboriginal Health Infostructure and Aboriginal participation within the Canada Health **Info**way.

Developing Health Information Resources

Several key initiatives are under way which have the potential to provide vital information sources for the Aboriginal Health Infostructure.

The first is the *First Nation and Inuit Regional Longitudinal Survey*, which arose in the context of a National Longitudinal Survey funded by Health Canada in 1996 after a pan-Canadian consultation. The regional survey involved nine regions, each of which developed and conducted its own survey process within the framework of the national survey. The purpose was to facilitate a process owned and controlled by First Nations and Inuit that involved community-based participatory research and surveillance of health status and health determinants; and an evaluation of health care delivery over time. The initial phase of the project is now nearing completion. The AFN has mandated moving to the next phase, a longitudinal survey to be conducted every four years, starting in 2001.

In the Council's view, the First Nation and Inuit Regional Longitudinal Health Survey Project provides a unique opportunity for First Nation and Inuit peoples to own, control, manage and validate a pan-Canadian research process. The survey will also supply important health data and community information, help identify health and social priorities, and provide a basis for evaluating health programs and services.

Recommendation

7.4 Health Canada, in partnership with other federal departments, should support and fund the First Nation and Inuit Regional Longitudinal Health Survey process. This would enable a sustained, ongoing, comparable source of First Nation and Inuit population health information, data collection, research and analysis capacity within a process validated and supported by First Nation and Inuit peoples, regionally and nationally.

The First Nations Health Information System (FNHIS) is a community-based health information and surveillance system now being used by 45 First Nations communities. Health Canada plans to make it available by March 2000 to all First Nations, primarily through web-based technologies.

The FNHIS will strengthen the health information and surveillance capabilities of First Nations communities. However, for this potential to be fulfilled and the initiative to be sustainable at the community level, local users will need computer skills and training in information management. In addition, communities will need a reliable communications infrastructure capable of supporting high-speed data transfers. Finally, it will be important to recognize the principle of Aboriginal control over Aboriginal data. For all these reasons, it is the Council's view that, while the FNHIS deserves support, this should be provided in the context of developing a comprehensive Aboriginal Health Infostructure.

Recommendation

7.5 Health Canada should provide additional resources for the First Nations Health Information System, but only on a sustainable basis and in the context of developing a comprehensive Aboriginal Health Infostructure which will involve a multifaceted, interlinked process involving many initiatives; some currently under way and others to be developed.

Improving the Communication Infrastructure

Most remote and rural Aboriginal and non-Aboriginal communities lack the communications infrastructure to support reliable high-speed transmission or reception of data, images or text. Few such communities can support reliable transmission at 28.8K, generally considered the minimum for Web browsing. Technical problems are common among many of the older cable, analog satellite or microwave links used to bring in information to these communities. Most remote communities lack toll-free access to an Internet Service Provider, which makes Internet use too expensive. In the Council's view, the current communications infrastructure in rural and remote Aboriginal and non-Aboriginal communities alike should be assessed as a matter of urgency, with a view to ensuring high-speed data transmission and a level of affordable, high-quality service.

Recommendation

7.6 Health Canada should take the lead, with other federal departments, to ensure that the state of the communication infrastructure in Aboriginal and non-Aborignal communities alike is assessed in order to undertake technical enhancements to support high-speed data transmission and enable accessible, affordable and reliable use of the Canada Health **Info**way.

Building Health by Building Infostructure

Virtually all analyses of the impact of health determinants emphasize the negative effects on health of the poverty and unemployment endemic to many Aboriginal communities. For this reason, the Council believes that, to the degree possible, the economic benefits of building an Aboriginal Health Infostructure should stay within Aboriginal communities. Such an approach means providing the appropriate training opportunities for members of those communities, co-venturing with Aboriginal businesses and giving them access to tenders, involving the entire community in the development of the infostructure, and so on. This partnering approach, combined with the provision of training, will also ensure that the human resource basis exists within the community to support and fully take advantage of the Aboriginal Health Infostructure.

> "Saskatchewan's largest non-government Internet provider is owned by First Nations. File Hills Internet, started in 1995 by the Peepeekisis First Nation of Saskatchewan and now owned by the five First Nations of the File Hills Tribal Council, has aggressively moved into the Internet market via formal partnerships. This has provided opportunities for First Nations in construction, technology hardware maintenance and has opened the door to advancement in future technologies. For the president of the File Hills consortium, economic development means 'quality jobs that (First Nations) people can do, not labour-intensive jobs, not make-work projects, but good sound career opportunities in many different fields of business.'"
>
> *Assembly of First Nations*
> *November 1998*

Recommendation

7.7 Health Canada, in partnership with other federal departments, should make a sustained commitment to the development of an economic infrastructure, as it relates to the development and implementation of the health infostructure in Aboriginal communities. In doing so, the health infostructure initiative will facilitate employment, career development, capacity building, increased economic development, personal and community income, community stability, training opportunities and improvements to the health and social condition of Aboriginal peoples.

chapter eight

Technology Transfer and Public-Private Sector Collaboration

New information and communications technology remains one of the foundations for the Canada Health **Info**way. This technology is continuing to change very quickly. It will be critical to have mechanisms in place that will allow the health sector to monitor developments and adopt the most cost-effective solutions. Collaboration between public and private sectors represents one of several promising approaches.

Technology Transfer

The ongoing revolution in information and communications technology remains one of the driving forces behind the development of the Canada Health **Info**way. The transformations have been profound. For the last 25 years, the speed of computers has been doubling every 18 months. Some would argue that the capacity of our communications systems has been doubling at about the same rate. The Internet is only one of the most apparent results of this technological revolution. Less visible are the ongoing advances in satellite and wireless technologies. These increasingly have the potential to bring powerful communications links into remote and rural areas and other locations where wires are impracticable or less effective.

Some segments of the health sector have been quite slow in adopting information and communications technology. This is partly because of a concern about technology's impact on the relationship between patient and physician or provider which lies at the foundation of health care. For this reason, it will be critical to ensure that health infostructure applications strengthen this relationship.

However, it is also necessary to recognize that this relationship is changing. For example, patients and people in general increasingly look to sources of health information in addition to consulting their health care professional and provider. They worry that both the quality and accessibility of health care are declining. They are demanding greater accountability from the system at all levels. As Chapters 2, 3 and 4 demonstrate, information and communications technology, properly deployed and used, can strengthen the provider–patient relationship by responding to these concerns. At the same time, it can provide feedback as a basis for continuous improvement in the health care system.

It is also important to appreciate that the pace of change will continue to accelerate. In five years, the technological landscape may look very different. New health care applications in the areas, for example, of tele-homecare or telehealth will likely have far-reaching implications and provide the basis for new kinds of services to patients and the public. Ultimately, there may be a move from personal computing (where people have a computer on their desktops) to pervasive computing, where chips are embedded in a wide range of everyday office, household and health products. This change could well eliminate many of the problems associated with today's applications of information and communications technology.

"New health care applications in the areas, for example, of tele-homecare or telehealth will likely have far-reaching implications and provide the basis for new kinds of services to patients and the public."

For this reason, it will be necessary to ensure that the health sector has an effective means of monitoring relevant technological developments. Evaluations of health applications of technology and information on best practices in deploying it for health purposes continue to accumulate in Canada and around the world. It will be important to gather, collate and disseminate these data throughout Canada's health sector. It will also be vital to promote, using incentives and other means, innovative uses of the technology to deliver health information and health care services. Finally, because human interaction and the relationship between provider and patient are so central to health care, the human and behavioural aspects of using the technology deserve careful attention.

In the Council's view, Health Canada should take the lead, with provincial and territorial health ministries, other federal departments, and associations of health care professionals, providers and institutions, in involving association members to carry out these tasks.

Recommendation

8.1 Health Canada should take the lead in developing, in cooperation with provincial and territorial ministries, other federal departments, and associations of health care professionals, providers and institutions, a process to involve health care professionals, providers and institutions in:

(a) monitoring technological developments in Canada and around the world that may be relevant in delivering health information and health care services;

(b) gathering, collating, disseminating and using information from Canada and around the world on best practices and evaluations in ways of deploying information and communications technology in health;

(c) promoting, through incentives and other means, ongoing innovation in using information and communications technology to deliver health information and health care services; and

(d) addressing the human and behavioural impacts of adopting information and communications technology in health.

Public-Private Sector Collaboration

Collaboration between the public and private sectors can be an effective means of ensuring the development or adoption of technology within the health field. In this context, we mean such technology as hardware, software, systems design, system architectures, etc. We do not mean data or service delivery, which can raise sensitive issues, including the possibility of gradual privatization.

The terms "public sector" and "private sector" can each comprise a wide variety of different kinds of organizations. For example, the public sector can include government and many different types of public agencies with different degrees of accountability to government. The private sector can include companies whose primary aim is to make a profit, as well as not-for-profit organizations such as the Canadian Network for the Advancement of Research, Industry and Education, some research centres and a range of non-governmental organizations, as well as others.

Collaborations can involve combinations of all these different types of organizations. It is in keeping with the Council's cooperative vision of the Canada Health **Info**way that its development and implementation, at least in terms of technology development, will involve collaboration among the public sector and private not-for-profit and for-profit organizations.

The rationale for the public sector's collaboration with its private sector counterpart usually revolves around a desire for a commercial product or a need to leverage resources, or acquire skills or access to expertise not present in the public sector. If the financial resources or necessary technological expertise do not exist in the public sector, collaboration with the private sector can enable more rapid technological development at less cost than if the public sector first had to develop the necessary expertise in-house.

The rationale for the private sector's collaboration with its public sector counterpart usually is due to Canada's small and fragmented market. Collaboration with the public sector opens up a critical portion of this market and helps provide a firm domestic base for export.

In the Council's view, collaborations between public and private sectors in the area of technology development can add value and advance the building of the Canada Health **Info**way. The scope of possible arrangements is great, and individual circumstances will largely dictate contractual terms. However, the Council believes that government has the responsibility to define clearly its approach to public-private collaboration and transparently examine its implications in light of the following principles:

- all such collaborations must pay fastidious attention to safeguarding privacy and protecting health information;
- all such collaborations should respect and reinforce the principles of the *Canada Health Act*;
- all such collaborations should respect and reinforce public administration of the health system;
- as part of the normal contracting process where intellectual property with a potential for commercialization is likely to be developed, the return to the parties should be in line with the contributions made and the risks assumed by the parties; and
- to the extent possible, commercialization of intellectual property should occur in Canada.

chapter nine

A Strategic Investment

Funding for the Canada Health **Info**way is not an investment where short-term payoffs provide a sufficient rationale. The Canada Health **Info**way is a strategic infrastructure that will transform and have impacts on the Canadian health care system and the health of Canadians in the long term. It is a positive revolution in the making. Investments in health infostructure – and in its essential building blocks at the provincial and territorial level – must take the long-term view. Through such investments, we will help create the Canadian health care system of the 21st century – one in which the public attains a new level of empowerment, health care services are stronger and much more integrated, new information resources enhance accountability and decision making at all levels, and privacy protection is significantly improved.

An Infrastructure for the 21st Century

At present, many provincial and territorial health infostructures have difficulty securing funding, even though these will have a far-reaching positive impact on provincial and territorial health care systems and will be vital parts of the Canada Health **Info**way. The Canadian health care sector also lags considerably behind other sectors of the economy and the US health care industry in investment in information systems. The present Canadian situation also contrasts sharply with developments in the United Kingdom where, as Chapter 1 notes, the British government is planning to put more than £1 billion into its health information strategy for the National Health Service over the next seven years. Other governments of industrialized countries are preparing to do the same.

In all of these examples, the rationale for the investment depends only partly on short-term gains, which certainly do exist. The main focus is on strategic gains that will manifest themselves over the long term as better ways of delivering health care services and using information. Various Canadian stakeholders, including those operating provincial and territorial health information systems, have told the Council that it is impossible to develop a strategic new way of delivering health care services and information with long-term benefits by pulling funds out of existing health capital and often declining operating budgets. The Council agrees with this view. Without new money, most provincial and territorial health infostructures will not be realized and the Canada Health **Info**way will not come into existence.

As the Canadian Practical Nurses Association pointed out in its comments on our interim report, "It is imperative that these initiatives be funded with 'new' money rather than withdrawals from the current cash-strapped system. Done right, this health infostructure has the potential to alter, positively, the way information is shared and utilized to the benefit of the health of Canadians. This will take money, and cannot occur at the expense of other programs and services that have already incurred near-mortal wounds."

*"Developing a Canadian health infostructure can be compared to building a transcontinental railroad or highway, but this time it is our health care system in the knowledge society and digital world of the 21st century.... We believe investments in the Canada Health **Info**way will be of similar benefit for the health care system and the health of Canadians."*

Investment in the Canada Health **Info**way or its provincial and territorial foundations is clearly not an investment like any other. The infostructure is a strategic, pan-Canadian infrastructure, and its funding should be regarded as a strategic, national infrastructure investment decision. Developing a Canadian health infostructure can be compared to building a transcontinental railroad or highway, but this time it is our health care system in the knowledge society and digital world of the 21st century. While many were uncertain about investments in the railroad in the 1870s or in an electric power grid at the turn of the century, few would disagree now about the transformations and effects brought about by those strategic infrastructure investments. We believe investments in the Canada Health **Info**way will be of similar benefit for the health care system and the health of Canadians. These effects are readily apparent if we look at where we are now and where we can be if we carry through on the Council's strategic framework and the initiatives recommended in this report.

Investments in the Canada Health **Info**way can also create industrial and economic opportunities for Canada. Development of a national health infostructure is on the agenda of virtually every industrialized country in the world. Canada is an acknowledged world leader in telecommunications. If we invest now in the Canada Health **Info**way and act on the recommendations in this report, we also could become world leaders in the development of a health infostructure. With this lead, it would be possible to build on our telecommunications expertise to develop and export network solutions and a range of software applications in health. These include disease surveillance systems, a variety of decision-support tools to facilitate evidence-based decision making, and applications to support consumer access to quality health information. In the course of building the **Info**way, these will have been developed in close cooperation with health care professionals and providers and will therefore be of practical value to their counterparts in health care systems around the world. The industrial and economic opportunities for Canada will be very significant.

From Promise to Reality

The Council is convinced the Canada Health **Info**way is a strategic element for the Canadian health care system. We believe it will be critical to ensuring that this publicly funded and administered system can meet the challenges and seize the opportunities of the 21st century. The Council also believes that, by empowering people, by responding to Aboriginal needs, by improving both the quality and accessibility of health care services, the Canada Health **Info**way will respond to the deeply held values of compassion, caring and equity which provide the foundation for Medicare in Canada.

The Council also believes that very few Canadians understand what a health infostructure is or what it can accomplish. For this reason, we consider it a matter of utmost importance that federal, provincial and territorial governments undertake a public awareness campaign at the community level to ensure that people have an opportunity to grasp the importance of and need for infostructure investments and become involved in developing the Health **Info**way.

Provincial and territorial health information systems represent the building blocks of the Canada Health **Info**way. But often there is far too little collaboration, information sharing and mutual learning from systems evaluations to ensure that the benefits derived from them are fully understood. It is important to emphasize that health infostructure systems should be judged not for their advanced technologies but for their actual contribution to the health of Canadians.

Finally, however fundamentally important provincial and territorial health infostructure initiatives may be, they may not meet all national needs. Such needs must be identified and addressed by Health Canada in partnership with provincial and territorial health ministries.

Recommendation

9.1 In partnership with provincial and territorial ministries of health, Health Canada should:

(a) undertake public awareness and participation campaigns at the community level to underscore and give a high profile to the importance of strategic health infostructure investments;

(b) promote collaboration, information sharing and mutual learning with respect to the evaluation of health infostructure initiatives and the benefits to be derived from them;

(c) ensure that all health infostructure projects and programs demonstrate the relationship of their proposed objectives and expenditures to the goal of improving or maintaining the health of Canadians and that they contain evaluative mechanisms to that effect; and

(d) identify and meet national needs that remain unaddressed by provincial and territorial health infostructure initiatives.

As mentioned earlier, the Council was repeatedly told that without new money the present set of ambitious provincial and territorial health infostructure initiatives will suffer and new ones will disappear at the conceptual stage. For this reason, the Council believes that, in transferring funding for health purposes to provincial and territorial governments, the Government of Canada should work with provincial and territorial governments to ensure that a portion goes to development of their health infostructures, that they collaborate in developing the Canada Health **Info**way, and that their own plans and priorities are set within the context of a jointly developed Canadian health infostructure.

Recommendation

9.2 In transferring funds to provincial and territorial governments for health purposes, the Government of Canada should work with provincial and territorial governments to ensure:

(a) allocation of a portion of the funding to developing provincial and territorial health infostructures;

(b) mutual collaboration among provinces, territories and Health Canada on developing the Canada Health **Info**way, as detailed in this report; and

(c) implementing a system for all provincial and territorial governments to set their own plans and priorities in the context of the jointly developed Canada Health **Info**way.

chapter ten

Moving Forward

For most Canadians, our publicly administered health care system is so fundamental that it is a defining feature of our nationality. The Council believes that the Canada Health **Info**way can strengthen that system enormously, making it more accountable to Canadians and more capable of serving them effectively and efficiently – in short, in the way they have come to expect.

Telehealth and tele-homecare, for example, should greatly strengthen the quality and accessibility of health care in Canada – in rural and remote areas and in the home and community. Health information systems may well represent our best chance to fully and effectively integrate the many health care services involved in today's complex health system. This infostructure will also give people the information they need to make more informed decisions about their own health and that of others. One result will be better decisions by health professionals, administrators and policymakers. Another will be a new capacity of patients and individual Canadians to take control of their own health and hold the entire health sector to higher standards of accountability. Another consequence will be improved privacy protection within the health sector.

In light of these objectives, we have set down broad strategic directions on how to develop and implement the Canada Health **Info**way. With publication of this report, the Council's work and mandate are over.

Now it is your turn. The task ahead is enormous. It involves building a new strategic infrastructure for our health care system – one that will ensure its capacity to survive and prosper in the 21st century as a publicly funded and administered health care system.

As a federal advisory council appointed by a health minister, the Council has directed many of its recommendations to the Minister of Health and Health Canada. But we wish to emphasize that this is a job that will involve more than one minister and one department. We anticipate that a number of federal departments and agencies will have to contribute to the building of the Canada Health **Info**way.

Most important of all in this endeavour will be close partnership and ongoing participation with provincial and territorial governments, particularly their health ministries which carry most of the responsibilities for health care delivery.

But collaboration will also have to extend beyond governments to health care professionals and providers, health care institutions, health managers, health researchers and health policy-makers. It will also be critical to involve the associations representing all these groups, as well as both the for-profit and not-for-profit segments of the private sector.

Most of all, the Council believes that it is critical that the public be involved in shaping the Canada Health **Info**way. As patients, as caregivers, as citizens, as health consumers, people must use their influence to ensure that the Canada Health **Info**way meets their needs and improves health care. The infostructure must ultimately serve as a fundamental way to ensure that our health care system remains fully accountable to the people using it.

Glossary

encryption – The coding of data for privacy protection or security considerations.

health infostructure – The application of communications and information technology in the health sector to allow the people of Canada (the general public, patients and caregivers, as well as health care providers, health managers, health policymakers and health researchers) to communicate with each other and make informed decisions about their own health, the health of others, and Canada's health system.

information exchange protocols – Standards that typically define message formats for the electronic exchange of information. Some information exchange protocols also define codes for specific fields in the messages. *See standards.*

information privacy – A subset of privacy, it involves the right of individuals to determine when, how and to what extent they will share personal information about themselves with others. Protecting information privacy involves protecting personal information and following fair information practices. *See privacy.*

Internet – A vast international network of networks that enables computers of all kinds to share services and communicate directly. It is the largest and fastest growing international computer network, and links individuals, and academic and commercial organizations.

personal information – Any information about an identifiable individual that is recorded in any form, including electronically or on paper. Some examples would be information about a person's religion, age, financial transactions, medical history, address or blood type. *See privacy.*

privacy – Most often defined as the right to be left alone, free from intrusion or interruption, privacy is an umbrella term, encompassing elements such as physical privacy, communications privacy and information privacy. Privacy is linked to other fundamental human rights such as freedom and personal autonomy.

public key cryptography – A form of cryptography that uses a cryptographic algorithm which uses two related keys: a public key and a private key. The two keys have the property that, given the public key, it is computationally infeasible to derive the private key. Public key cryptography is also called "asymmetric cryptography." There are three broad functions of public key cryptography systems: (1) encryption/decryption; (2) digital signatures; and (3) key exchange. Some algorithms can perform all three functions and some can perform only one.

public key infrastructure (PKI) – A structure of hardware, software, people, processes and policies that employs digital signature technology to facilitate a verifiable association between the public component of an asymmetric public key and a specific end entity. The public key may be provided for digital signature use and/or for message encryption key exchange or negotiation.

standards – Documented agreements containing technical specifications or other precise criteria to be used consistently as rules, guidelines or definitions of characteristics to ensure that materials, products, processes and services are fit for their purpose.

technical standards – Standards describing the specific attributes of technology. This may include specifications for physical interfaces. *See standards.*

telehealth – Use of information and communications technologies in the delivery of health information, services and expertise over short and long distances.

tele-homecare – The use of electronic communication networks for two-way transfer of information and data required for medical diagnosis, treatment, consultation and/or health maintenance between a patient's residence and a health care facility.

Annex A

Advisory Council on Health Infostructure

Members

Richard Alvarez is the President and Chief Executive Officer of the Canadian Institute for Health Information (CIHI). Mr. Alvarez has had a distinguished career in the Canadian health sector, both at the national and provincial levels. He has served as Chairman of the National Health Information Council (NHIC), as the Chairman of the Interim Board of the CIHI and has been a Trustee of Alberta Blue Cross. Before joining the Institute, Mr. Alvarez was an Assistant Deputy Minister with Alberta Health.

Danièle Bertrand is one of the leading executives in the Canadian telecommunications industry. She is President of the Innovation Centre, which was established by Stentor in 1996. As President, she is responsible for identifying and promoting new businesses in the field of telecommunications. She works with leaders in innovative technologies and with the nine telcos that comprise the Stentor Alliance. It is a position that draws on her creative business, diplomatic and technology abilities. Before her current appointment, Ms. Bertrand was Managing Director, Corporate Development, at Stentor Resource Centre Inc. Her responsibilities as Managing Director included strategic and financial planning, market research and evaluating business opportunities.

Andrew Bjerring has been President and Chief Executive Officer of the Canadian Network for the Advancement of Research, Industry and Education (CANARIE) since October 1993. His involvement as a founding member and Secretary of the Board of Directors with CANARIE dates back to its beginning in 1990. Before his appointment at CANARIE, Dr. Bjerring spent nine years as Director of Information Technology Services, and six years as Assistant Vice President (Academic Planning and Budgeting) at the University of Western Ontario.

Madeline Boscoe is Executive Coordinator of the Canadian Women's Health Network (CWHN). The CWHN's key goal is information exchange and networking for consumers, community groups, researchers and providers, through mechanisms such as an on-line clearinghouse. In this capacity, the CWHN is an active participant in the Centres of Excellence in Women's Health Research program. She has lengthy experience in the areas of health promotion, community development and policy analysis, most recently with the Women's Health Clinic, a community health centre in Winnipeg.

George Browman is the Scientific Program Leader of HEALNet (Health Evidence Application and Linkage Network) and Professor and Chair of the Department of Clinical Epidemiology and Biostatistics at McMaster University. He also leads the Ontario Cancer Treatment Practice Guidelines Initiative and, in September 1997, he became Director, Program in Evidence-based Care for Cancer Care Ontario. He is still active as a medical oncologist and health sciences researcher. Dr. Browman maintains a clinical oncology practice at the Hamilton Regional Cancer Centre.

Monique Charbonneau is the President and Chief Executive Officer of the "Centre francophone d'informatisation des organisations" (CEFRIO). Her career has included management positions over a 10-year period with the federal government in Ottawa, Montreal and Quebec in the field of documentation and information. After working with the "Office de la langue française," Mme Charbonneau held a variety of positions in research and information technologies with the Quebec Ministry of Communications prior to joining CEFRIO. She was a member of the "Comité consultatif du Québec sur l'autoroute de l'information" and is presently a member of CANARIE Inc., ACFAS and a number of administrative councils.

Ivan P. Fellegi was appointed Chief Statistician of Canada in 1985. He was also Vice Chairman of the Board of the Canadian Institute for Health Information. Dr. Fellegi has published extensively on statistical methods, regarding the social and economic applications of statistics and on the successful management of statistical agencies.

Debbie L. Good is a Chartered Accountant and presently an Investment Advisor with Nesbitt Burns, Charlottetown, P.E.I. Ms. Good was a member of the National Forum on Health, serving on the Determinants of Health Working Group. She was also Chair of the P.E.I. Health Policy Council, a former Commissioner of the Hospital and Health Services Commission, and a former member of the Board of the Queen Elizabeth Hospital Foundation.

Doug Hull is currently Director General, Information Highway Applications Branch, Industry Canada. He is responsible for implementing key elements of Canada's national access strategy, including the effort to link all schools, libraries and rural communities to the Internet by 1998-99. He also has responsibilities related to fostering the conversion of public services for electronic service delivery and for stimulating the emergence of world-class telelearning and telehealth sectors in Canada.

Mary Ellen Jeans is the Executive Director of the Canadian Nurses Association (CNA). Dr. Jeans has practised as a staff nurse, researcher, educator and administrator. Before her appointment to the CNA in 1996, she was Director General, Extramural Research Programs Directorate, Health Canada where she was responsible for the National Health Research and Development Program. From 1983 to 1992, she was Director, School of Nursing, McGill University in Montreal.

The Honourable Wilbert J. Keon is Director General of the University of Ottawa Heart Institute and also a Member of the Senate of Canada. Dr. Keon has sustained a leadership role in the surgical, academic and scientific community throughout his career. Dr. Keon has led the development of the Heart Institute which has become one of the world-leading academic and health care centres.

André Lacroix is an endocrinologist at Hôtel-Dieu pavillion of Université de Montréal Teaching Hospital (CHUM) in Montreal, and a Professor of Medicine and Director of the Endocrinology Training Program at Université de Montréal. He is also Co-director of the Telemedicine Unit of the CHUM Research Centre and President of the "Comité central du réseau inter-régional de télémédecine au Québec." Dr. Lacroix is the Canadian representative on a G-7 group of experts in telemedicine systems where he is the coordinator of the Subproject 4 in telemedicine of the G-7 Global Health Care Applications Project.

Cameron Mustard is an Associate Professor in the Department of Community Health Sciences, Faculty of Medicine, University of Manitoba, with active interests in health services research in the areas of mental health, pediatric care, obstetrics and in chronic disease epidemiology with a focus on socio-economic disparities in health status and the utilization of health services. Dr. Mustard is a member of the Manitoba Centre for Health Policy and Evaluation and has recently been appointed to a five-year term as an Associate of the Population Health Program of the Canadian Institute for Advanced Research.

David Naylor is Professor of Medicine at the University of Toronto. A Senior Scientist of the Medical Research Council of Canada, Dr. Naylor has received national and international awards for his contributions to health services research. He was the founding chief executive officer of the Institute for Clinical Evaluative Sciences, which generated Canada's first detailed report cards on health status and health care with its Ontario-based "Practice Atlas" series. Dr. Naylor is also a staff physician at the Sunnybrook and Women's College Health Sciences Centre.

Tom W. Noseworthy, co-chair, is Professor and Chair of Public Health Sciences, Faculty of Medicine and Dentistry, University of Alberta. He is an internist and critical care physician. He served as a member of the Prime Minister's National Forum on Health, in which he was a member of the Evidence-based Decision Making and Striking the Balance Working Groups, and Chair of the Steering Committee. Dr. Noseworthy's past appointments include President and Chief Executive Officer and Vice-President – Medical Services of the Royal Alexandra Hospital, Edmonton. He currently chairs the Senior Reference Committee of Alberta We//net, the province's health information system.

Alan B. Nymark, co-chair, is Associate Deputy Minister of Health Canada. Prior to this appointment, he was Assistant Deputy Minister of Industry and Science Policy at Industry Canada. Mr. Nymark joined the Public Service in 1972 and has held various senior-level positions, for example, with the Privy Council Office, Department of Finance, and as Assistant Chief Negotiator on the Canada/U.S. Free Trade Agreement and subsequently the North American Free Trade Agreement. Mr. Nymark has worked in the private sector as a special advisor to the Royal Bank of Canada and with the International Monetary Fund in Washington, D.C.

Robert Perreault is the Chief of Preventive Medicine (HMR), Public Health Directorate, Montreal Centre. He is also a Professor, Faculty of Medicine at the University of Montreal and an Assistant Professor, Faculty of Medicine at McGill University. In addition, Dr. Perreault is Co-director of the Research Centre on Health Promotion in Montreal.

Jeff Reading obtained PhD (1994) and Master of Science (1990) degrees from the Department of Community Health at the University of Toronto. At present, Dr. Reading splits his time between an academic appointment as Assistant Professor at the Department of Community Health Sciences, University of Manitoba, and as a private health research consultant based in Victoria, British Columbia. Dr. Reading's research interests include the general area of Aboriginal health with specific research projects concerning the non-traditional use of tobacco by Aboriginal peoples, First Nations heart health, diabetes, Aboriginal Head Start early childhood education and community-based health promotion for Aboriginal children. Dr. Reading is a Mohawk from southern Ontario and lives with his family in Victoria, British Columbia.

Carl Robbins is Vice-Dean, Professional Development, and Chair of Telemedicine at the Faculty of Medicine, Memorial University of Newfoundland. Prior to this he was Chair of Family Medicine at the medical school. Past appointments include Medical Director of the General Hospital Corporation in St. John's and Interim CEO of the Newfoundland Cancer Treatment and Research Foundation. His interest in the delivery of health care services to rural and isolated environments spans three decades and has included involvement in Memorial University's early telemedicine research and development projects.

Dorothy Spence is the co-founder, President and Chief Executive Officer of TecKnowledge Healthcare Systems Inc., a Canadian telemedicine company. Ms. Spence's background is in biomedical engineering consulting, sales and business management in the health care industry.

H. William Thomson, Vice President and Branch Manager of Sierra Systems Consultants Inc. – Victoria office is responsible for the firm's British Columbia's health industry consulting. He is actively involved in management positions within health care organizations, high-level feasibility studies and strategic systems planning. Since 1984, Mr. Thomson's health care experience has included various management positions and health initiatives throughout North America.

Mamoru (Mo) Watanabe, Professor Emeritus of Medicine, is former Dean of the Faculty of Medicine at the University of Calgary. Dr. Watanabe is a researcher and medical educator, past Chair of the Board of CANARIE, member of the National Cancer Institute of Canada's Committee on Planning and Priorities, Alberta Health's Senior Reference Committee and Provincial Telehealth Committee. He was an advisor to the Medical Research Council on health research and a former member of Industry Canada's Information Highway Advisory Council and the Prime Minister's National Forum on Health.

John A. Williams is President and Chief Executive Officer of *Smart*Health, a jointly owned subsidiary of EDS Canada and Royal Bank. *Smart*Health has been contracted by the Province of Manitoba to design, develop and implement a province-wide Health Information Network.

Frank Winter is Director of Libraries for the University of Saskatchewan Libraries. Before moving to the University of Saskatchewan in 1980, Mr. Winter held positions with the University of Windsor Law Library and the University of Windsor Library.

Special Advisors to the Council

Pierrôt Péladeau
Centre for Bioethics
Clinical Research Institute of Montreal

Bettylynn Stoops
Health Promotion and Programs Branch
Health Canada

Office of Health and the Information Highway – Health Canada

Director General
Andrew Siman

Advisory Council on Health Infostructure Secretariat

Director
Michel Léger

Senior Analysts
Jean-Claude Barre
Patricia Scotcher
Stephen Vail

Analyst
Joyce Adubofuor

Logistics Coordinator
Carmel Cullen

Administrative Support
Maria Rocha-Hug

Report Writer
John Sifton

Annex B

List of Recommendations

Recommendations from Final Report

1. Toward a Healthier Canada

Cooperation – the Critical Success Factor

1.1 The federal government has a responsibility to foster mutual cooperation and collaboration among provincial and territorial governments, Aboriginal communities and all stakeholders in developing and implementing the Canada Health **Info**way.

2. Empowering the Public

Health Information for the General Public

2.1 Health Canada, in partnership with provincial and territorial ministries of health, should recognize in its funding decisions for a health infostructure that health information is an essential public good which should be readily available and accessible to all Canadians as a component of Canada's publicly funded health system.

2.2 To understand better the information needs of the public, strengthen people's ability to access and use evidence-based information, and provide mechanisms for public access to reliable health information, Health Canada should:

(a) undertake, in partnership with other levels of government and health stakeholders, an investigation of the health information needs of the general public, using a variety of culturally and linguistically appropriate, interactive and ongoing strategies;

(b) promote, in partnership with other federal departments and agencies (e.g. the Canada Institute for Scientific and Technical Information) and provincial and territorial departments and agencies, the ability of Canadians to access and use evidence-based, non-identifiable health information to meet their health information needs and concerns by establishing a fund that will support demonstration projects;

(c) establish a fund to allow consumer and health intermediaries to develop and provide access to consumer health information; and

(d) support the Canadian Health Network as one mechanism for providing Canadians with access to reliable health information.

2.3 Health Canada, in partnership with provincial and territorial health ministries, should take the lead to:

(a) ensure that standards/benchmarks/guidelines are developed and implemented to allow the general public to distinguish objective, empirically based health information from information intended to promote a product; and

(b) expand these standards/benchmarks/guidelines eventually to include rating criteria for websites providing health information.

2.4 Health Canada should work with other health stakeholders to:

(a) ensure that health concerns such as consumer protection with respect to health products and services are adequately reflected in the present work of federal, provincial and territorial governments to develop legislative and regulatory frameworks for electronic commerce on the Internet; and

(b) take appropriate alternative action if health and safety issues are not adequately reflected in this work.

2.5 Health Canada should work with other federal departments and agencies and specialists in the field to encourage development of:

(a) an Internet search capability which is specific to health and, at a minimum, fully and equally meets the needs of Canada's English- and French-speaking communities; and

(b) Internet content on health in French and English.

2.6 Health Canada, in partnership with representatives of user communities such as the Canadian Association of Public Data Users, should take the lead in approaching Treasury Board and other federal departments and agencies to review the policies and practices with respect to cost recovery and revenue generation governing the availability and redistribution of publicly funded collections, statistical databases and other government information relevant to health.

Ensuring Access

2.7 Investments in the digital networking of the Canada Health **Info**way should be balanced by appropriate investments in the other (i.e. non-electronic) mechanisms for sharing information that can lead to improved health.

2.8 To ensure that health information is accessible on a universal, equitable and affordable basis, it is vital that:

(a) the federal government continue to ensure universal, equitable and affordable access to existing and future basic telecommunications infrastructure; and

(b) Health Canada, in partnership with provincial and territorial ministries of health, take a leadership role in ensuring that health information and health care applications for the general public are developed in such a way as to be accessible to all citizens, irrespective of their geographic location, income, language, disability, gender, age, cultural background or level of traditional or digital literacy.

2.9 Health Canada, in partnership with other federal departments, provinces and territories, and health stakeholders, should:

(a) ensure establishment of a "Canada Health Space" as a universally accessible health information/communications commons;

(b) capitalize on and support the nation-wide networking of health intermediaries;

(c) ensure adequate funding and technical support to health intermediaries to develop and/or maintain their capacity to provide the general public with timely, credible and "understandable" health information and to assist in overcoming access barriers; and

(d) accept, as a normal budgeted cost of doing business electronically, the need to sustain health intermediaries and support them for providing affordable electronic health information services to disseminate health promotion, health protection and other kinds of health information to wider publics, just as such costs have been accepted in the paper-based world in the past.

2.10 Health Canada, in partnership with provincial and territorial ministries of health, should work closely with Industry Canada to ensure that all public and not-for-profit health care institutions in Canada are aware of:

(a) the Community Access Program; and

(b) how they can apply for resources to locate public electronic access facilities on or near their premises to help ensure that their clients can use on-line health information.

2.11 As a means of ensuring more equitable access to health information and health care services, Health Canada, in partnership with provincial and territorial health ministries, should work closely with the Canadian Network for the Advancement of Research, Industry and Education, and Industry Canada to investigate the further integration of new technologies, including satellite technologies, into health networks at all levels.

Public Input and Accountability – Promoting Citizen Engagement

2.12 Health Canada should establish a non-governmental office of citizen health advocacy to coordinate and facilitate input and participation by the general public into health policy deliberations, including policies relating to the Canada Health **Info**way. This office would:

(a) coordinate and facilitate the linking of community-based voluntary health organizations and health consumer organizations to enable or enhance their capacity to participate effectively in health and public policy development; and

(b) constitute an ongoing, stable mechanism for obtaining reliable and representative input and feedback from the health consumer sector.

2.13 The office of citizen health advocacy should ensure production of assessments and evaluations of health sector activities relating to the general public. These would include setting agenda and critiques for report cards on the performance of health care programs and services, outcomes of interventions and treatments, and the actual health impact of health policies *(See also Recommendation 4.2)*.

3. Strengthening and Integrating Health Care Services

Supporting the Health Care Team

3.1 Federal, provincial and territorial governments should develop and test incentives to encourage and assist health care professionals and providers to adopt health infostructure applications. These applications include clinical decision support tools, health information systems and telehealth.

3.2 Federal, provincial and territorial governments, in collaboration with associations representing health care professionals and providers, should provide funding for:

(a) professional education and development opportunities for health care professionals and providers across the spectrum of health care to acquire the skills needed for optimal use of health information and communications systems; and

(b) developing, piloting and evaluating tools to support clinical decision making across the spectrum of health care.

3.3 Health Canada, in partnership with Human Resources Development Canada, other federal departments, provinces and territories, health worker organizations and health professional associations, should initiate a labour force strategy to:

(a) ensure the skills and knowledge base necessary to build, use and support the Canada Health **Info**way are available; and

(b) address labour policy, employment policy and occupational health and training issues.

Electronic Health Records

3.4 Patient-based health records are a fundamental cornerstone of provincial and territorial health infostructures. However, they have the potential for serious violations of privacy. The Council believes that, with particular care, electronic health records can actually enhance privacy protection, improve patient care, empower citizens through greater control of their own health records and serve as the foundation for an ever-improving information and evidence-based health system. Consequently, the federal Minister of Health should work with his provincial and territorial counterparts to bring about developments relating to provincial and territorial health systems that will:

(a) improve patient care by creating provincial and territorial person-based, electronic health record systems. These will make accessible, on a need-to-know basis and under the control of patients, all relevant information about their past medical histories, including conditions and diagnoses, as well as treatments, medications and other forms of intervention (whether publicly or privately funded);

(b) provide legislative safeguards against the use of identifiers for multiple purposes;

(c) improve the security of health records by exploiting modern technologies such as encryption, authentication and electronic logging of all accesses made to a personal record;

(d) ensure a transparent and harmonized approach across the country, in light of the principles enunciated in the report, to the conduct of ethical reviews on a case-by-case basis of proposed health research projects which require access to individually identifiable records and which, for whatever reason, cannot be conducted on the basis of informed consent by patients. (Such ethical reviews should assess whether there is a sufficiently substantive public good expected as a result of a proposed project to warrant the project and the implied invasion of privacy.) To these ends, federal, provincial and territorial governments should consider:

(i) establishing an independent oversight mechanism to ensure that ethical review panels across the country operate in a manner consistent with the principles enunciated in this report; and/or

(ii) creating, if necessary in their respective jurisdictions, ethical review panels which would operate in accordance with those principles;

(e) ensure that the evolving provincial and territorial health information systems have a system architecture that makes it possible to exchange information under strictly controlled circumstances; and

(f) harmonize provincial and territorial privacy legislation to ensure that these objectives are facilitated.

3.5 Health care professionals and providers and federal, provincial and territorial health ministries should engage the public in discussions on the value and use of electronic health records.

Seizing the Telehealth Opportunity

3.6 Federal, provincial and territorial Ministers of Health should promote the development of a Canadian strategy for telehealth by establishing a telehealth task force. This task force should be composed of representatives of health care professionals and providers and the full array of health stakeholders, including the general public. The mandate of the telehealth task force should be to:

(a) develop a Canadian strategy for funding and the integration of telehealth into health care delivery;

(b) develop technical and professional standards; and

(c) address issues regarding licensure, liability and reimbursement of health care professionals and providers.

3.7 To create a knowledge base for the telehealth task force and subject to evaluation by that task force, sufficient funding should be allocated to Health Canada to:

(a) develop, in partnership with provincial and territorial health ministries and associations of health care institutions and health professionals and providers, broadly accepted frameworks to assess the value of telehealth applications to physicians, health care professionals, providers and institutions, as well as the needs of these groups for such applications;

(b) undertake, in partnership with provincial and territorial health ministries and associations of health care professionals, providers and institutions, pilot and demonstration telehealth projects as a means of:

(i) evaluating within broadly accepted frameworks the costs and effectiveness of different applications and sets of applications, and

(ii) defining best practices;

(c) support national organizations (Canadian Society for Telehealth, Canadian Institute for Health Information, Canadian Network for the Advancement of Research, Industry and Education, and others) in their efforts to develop and implement the national telehealth strategy;

(d) support training for health care professionals and providers so that they can fully exploit the potential of telehealth; and

(e) support research, in conjunction with key stakeholders and the general public, on ethical, legal and social issues associated with telehealth.

3.8 To build a sound foundation for a Canadian telehealth strategy and to address the basic issues of cross-jurisdictional licensure, reimbursement and liability, it is vital that:

(a) professional licensing authorities develop a mechanism of licensure that will allow interprovincial telehealth consultations;

(b) each provincial and territorial government develop, and coordinate through the Federal/Provincial/Territorial Advisory Committee on Health Services, a telehealth reimbursement policy that includes interprovincial payment agreements for negotiated services, recognizing that:

(i) telehealth services are a legitimate way to deliver health care,

(ii) practitioners providing these services should be compensated, and

(iii) reimbursement for services are currently limited to face-to-face encounters; and

(c) providers of liability protection, such as the Canadian Medical Protective Association and the Canadian Nurses Protective Society, develop appropriate liability protection products for medical practitioners providing telehealth services.

4. Creating Information Resources

The *Health Information Roadmap* – An Action Plan for the 21st Century

4.1 The report, *Health Information Roadmap: Responding to Needs*, developed by the Canadian Institute for Health Information, Statistics Canada and Health Canada, fully articulates a plan for the creation of information resources to support accountability and continuous feedback on factors affecting the health of Canadians. The federal Minister of Health should commit the necessary levels of funding (as detailed in the report) to ensure – in the context of stringent privacy safeguards, confidentiality requirements and data security arrangements – successful implementation of the plan.

Report Cards on the Health Care System

4.2 As a key element of the *Health Information Roadmap*, the federal Minister of Health should, in partnership with his federal, provincial and territorial counterparts and health stakeholders across Canada, support evaluative analyses and consensus building to develop yardsticks and fair measures of health care system performance and the health status of Canadians. These analyses would form a basis for report cards to the public that will improve the overall accountability of the health care system.

Need for a National Health Surveillance Network

4.3 Federal, provincial and territorial Ministers of Health should collaborate in supporting the development of a National Health Surveillance Network that will allow the timely monitoring of the health of a region, a province, a territory or the nation as a whole in a global context.

5. **Improving Privacy Protection**

Key Legislative Mechanisms

5.1 In harmonizing and strengthening the protection of personal health information across jurisdictions, governments should ensure that their privacy legislation for health embodies the following mechanisms and principles:

(a) a clear definition of health information, broad enough to incorporate health information collected in public and private systems and to ensure that equal obligations and penalties apply to both public and private sectors;

(b) a definition of personal health information, which takes into account the spectrum of potential identifiability in the case of health information;

(c) a definition of a custodian or trustee of personal health information, and a custodian or trustee's obligations, including provisions for ensuring that these obligations apply equally to private sector organizations and organizations acting as an agent or contractor for the custodian;

(d) definitions of a guardian (e.g. for a minor child or a mentally incompetent person) and of a guardian's obligations;

(e) a definition of what constitutes informed consent, as well as a clear statement of principle to the effect that informed consent should be the basis for sharing information;

(f) a precise definition of "exemptions" to this requirement for informed consent – specifically provisions that give clear guidance on how to balance the right of privacy with the public good for research purposes;

(g) provisions prohibiting all secondary commercial use of personal health information;

(h) provisions setting clear limits on access and use of health information by third parties outside the health care system;

(i) provisions regulating secondary uses of non-identifiable health information, taking into account the spectrum of potential identifiability of such information;

(j) provisions prohibiting the use of personal health identifiers for other purposes, to prevent the potential serious invasions of privacy attendant upon potential access to personal health information beyond the health domain or the combination of records from several different areas to assemble a comprehensive profile; and

(k) provision for remedies in the case of breaches of privacy.

6. **Standards**

Developing and Implementing Compatible Standards

6.1 To strengthen significantly the development and implementation of standards in health informatics and telematics, it is necessary that:

(a) federal, provincial and territorial governments provide sufficient funding for standards development in health informatics and telematics to the Canadian Institute for Health Information (CIHI);

(b) measures be taken to ensure citizen participation in the standards development process through, for example, the CIHI partnership initiative;

(c) CIHI achieve a formal process for identifying, ratifying and implementing standards with federal, provincial and territorial Deputy Ministers of Health to ensure buy-in from provinces and territories at the level of officials;

(d) CIHI play a lead role for Canada with respect to international standards deliberations in the area of health informatics and telematics (e.g. ISO TC 215); and

(e) Industry Canada and the Standards Council of Canada establish a standards development organization for health informatics and telematics, based on a partnership between CIHI and the Canadian Standards Association.

Testing for Compatibility

6.2 Health Canada should work with the Canadian Network for the Advancement of Research, Industry and Education, and others as appropriate, to ensure that test-bed facilities are available to analyse the compatibility of new health application products with other health applications, including those already being used on Canadian health networks.

6.3 Health Canada should provide incentives for provincial and territorial governments to develop and carry out joint projects that will refine and resolve compatibility issues in health networks across Canada.

7. An Aboriginal Health Infostructure

A Unique Approach to Health Information

7.1 Health Canada should consider an Aboriginal Health Infostructure, strategically interconnected to the Canada Health **Info**way, as an autonomous and distinct institutional development consistent with Aboriginal interests.

7.2 Health Canada should provide financial resources for Aboriginal groups to undertake further consultation and communications with governments, private sector groups and each other to confirm and further develop the concept of the Aboriginal Health Infostructure and define plans for its development and implementation and/or determine the nature and scope of Aboriginal participation in the Canada Health **Info**way.

Steps Toward an Aboriginal Health Infostructure

7.3 Health Canada should ensure that resources committed and dedicated for capacity development and training are designated for Aboriginal people to support the Aboriginal Health Infostructure and Aboriginal participation within the Canada Health **Info**way.

7.4 Health Canada in partnership with other federal departments, should support and fund the First Nation and Inuit Regional Longitudinal Health Survey process. This would enable a sustained, ongoing, comparable source of First Nation and Inuit population health information, data collection, research and analysis capacity within a process validated and supported by First Nation and Inuit peoples, regionally and nationally.

7.5 Health Canada should provide additional resources for the First Nations Health Information System, but only on a sustainable basis and in the context of developing a comprehensive Aboriginal Health Infostructure which will involve a multifaceted, interlinked process involving many initiatives; some currently under way and others to be developed.

7.6 Health Canada should take the lead, with other federal departments, to ensure that the state of the communication infrastructure in Aboriginal and non-Aboriginal communities alike is assessed in order to undertake technical enhancements to support high-speed data transmission and enable accessible, affordable and reliable use of the Canada Health **Info**way.

7.7 Health Canada, in partnership with other federal departments, should make a sustained commitment to the development of an economic infrastructure, as it relates to the development and implementation of the health infostructure in Aboriginal communities. In doing so, the health infostructure initiative will facilitate employment, career development, capacity building, increased economic development, personal and community income, community stability, training opportunities and improvements to the health and social condition of Aboriginal peoples.

8. Technology Transfer and Public-Private Sector Collaboration

Technology Transfer

8.1 Health Canada should take the lead in developing, in cooperation with provincial and territorial ministries, other federal departments, and associations of health care professionals, providers and institutions, a process to involve health care professionals, providers and institutions in:

(a) monitoring technological developments in Canada and around the world that may be relevant to delivering health information and health care services;

(b) gathering, collating, disseminating and using information from Canada and around the world on best practices and evaluations in ways of deploying information and communications technology in health;

(c) promoting, through incentives and other means, ongoing innovation in using information and communications technology to deliver health information and health care services; and

(d) addressing the human and behavioural impacts of adopting information and communications technology in health.

9. A Strategic Investment

From Promise to Reality

9.1 In partnership with provincial and territorial ministries of health, Health Canada should:

(a) undertake public awareness and participation campaigns at the community level to underscore and give a high profile to the importance of strategic health infostructure investments;

(b) promote collaboration, information sharing and mutual learning with respect to the evaluation of health infostructure initiatives and the benefits to be derived from them;

(c) ensure that all health infostructure projects and programs demonstrate the relationship of their proposed objectives and expenditures to the goal of improving or maintaining the health of Canadians and that they contain evaluative mechanisms to that effect; and

(d) identify and meet national needs that remain unaddressed by provincial and territorial health infostructure initiatives.

9.2 In transferring funds to provincial and territorial governments for health purposes, the Government of Canada should work with provincial and territorial governments to ensure:

(a) allocation of a portion of the funding to developing provincial and territorial health infostructures;

(b) mutual collaboration among provinces, territories and Health Canada on developing the Canada Health **Info**way, as detailed in this report; and

(c) implementing a system for all provincial and territorial governments to set their own plans and priorities in the context of the jointly developed Canada Health **Info**way.

Recommendations from Interim Report

Recommendation 1

All federal, provincial and territorial governments in Canada should ensure legislation is in place addressing privacy protection and specifically aimed at protecting personal health information through explicit and transparent mechanisms.

Recommendation 2

The Minister of Health should take the lead in encouraging an accord among provincial, territorial and federal governments to harmonize, taking into account best practices internationally, the approaches in their respective jurisdictions to privacy and the protection of personal health information around the need to:

(a) certify, in the case of consent for the release of personal health information, the conditions of consent and the identity of the person giving the consent, in addition to authenticating the consent itself;

(b) review, in the case of anonymous data, whether the data are indeed anonymous ("non-nominative") and cannot be linked back to any individual; and

(c) have ethical review panels established to weigh, in the case of uses of personal health information for research purposes where securing consent is impractical, the value of privacy against the significance of the public good that might be achieved by the research.

Recommendation 3

Canada should develop a strong, national capability for cooperatively managing the development and adoption of compatible standards in the areas of health information and telematics, with strong links to international standards deliberations.

Recommendation 4

Provincial and territorial governments should advance or combine their personal identifier systems in the health area only at such time as they have:

(a) put in place a legislative framework for privacy protection specifically designed to address personal health information;

(b) implemented privacy-enhancing technologies in their own jurisdictions; and

(c) ensured the compatibility of their electronic security infrastructures for health information in consultation with their respective privacy commissioners.

Recommendation 5

The federal Minister of Health should:

(a) affirm the critical importance of interoperability, in the context of appropriate privacy safeguards, to the contribution of a national health infostructure to strengthening and integrating health care services; and

(b) take the lead in gaining the support of provincial and territorial ministers for achievement of the level of interoperability required for this purpose.

Recommendation 6

Health Canada should encourage national collaboration in the formation of a plan for the development of technical and data standards that would permit the eventual evolution of a national health infostructure, keeping in mind that:

(a) many national priorities may be longer-term elements of the plan; and

(b) other national priorities, such as the integration of services across the spectrum of care, should have a shorter time horizon.

Canada